Female Genital Mutilation (FGM): An analysis of the silences in maternity care experiences of FGM survivors and the silences of health care professionals providing maternity care to FGM survivors.

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ABSTRACT

The consequences of female genital mutilation (FGM) during the perinatal period are significant, but the experiences of FGM survivors accessing maternity care are under-reported in the literature. This thesis reports on the analysis of experiences of FGM survivors in maternity care and the experiences of health care professionals providing such care.

This qualitative study was methodologically structured around the Sound of Silence framework which was developed for research with marginalised groups and communities. Two separate cohorts of participants took part in this study; 20 FGM survivors and eight health care professionals. FGM survivors met the inclusion criteria if, (i) they had given birth within the previous few days of data collection, (ii) they and their baby were of sufficient health to be discharged home and, (iii) were able to communicate in one of the languages identified for use in this study; namely Arabic, English and/or French. Health care professionals were excluded from this study if they had provided maternity care within the service where they FGM survivor participants had accessed care.

Data analysis was conducted using a combination of thematic and discourse analysis to interpret overarching themes and elicit silences in the dominant discourses that were interpreted across the data. The findings from the analysis suggest that health care professionals' education and training lacks the cultural context of FGM which seems to have an impact on the provision of maternity services for FGM survivors.

Although risk assessments appeared to be dominant in the discourse of maternity care, this discourse appears to constrain health care professionals in maternity services from providing culturally responsive care. This appeared to lead to a silence of cultural sensitivity when providing care to FGM survivors.

Themes that were interpreted from the data suggest that mental health services are not seamless in maternity services for FGM survivors which appeared to relate to constraints in care provision as well as knowledge and education and communication issues with and amongst health care professionals. This finding led to the conception of a novel model of cultural silence around FGM which can be used to determine cultural dissonance in health care settings. Furthermore, recommendations include the development of working groups of FGM survivors and key stakeholders in the co-design and production of clinical guidance and education for health care professionals. Strategic planning for the implementation of mental health care collaboration in maternity services is recommended as well as the requirement of further research of mental health care in maternity services for FGM survivors.

GLOSSARY OF TERMS

AWA – FC	African Women Are Free to Choose
BHRC	Bar Human Rights Committee
CQC	Care Quality Commission
DH	Department of Health
FGC	Female Genital Cutting
FC	Female Circumcision
FGCS	Female Genital Cosmetic Surgery
FGM	Female Genital Mutilation
FORWARD	Foundation for Women's Health, Research and Development
HSCIC	Health and Social Care Information Centre
MBRRACE	Mothers and Babies: Reducing the Risk through Audits and Confidential Enquiries
GMC	General Medical Council
GP	General Practitioner
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NMC	Nursing and Midwifery Council
NSPCC	National Society for the Prevention of Cruelty to Children
PTSD	Post-Traumatic Stress Disorder
RCM	Royal College of Midwives
RCN	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
SLWA-FC	Sierra Leonean Women are Free to Choose

UDHR	Universal Declaration of Human Rights
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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inspired me to undertake this study in order to discover the answers to some of the questions that I began to ask regarding FGM. Sandie later became one of my research supervisors and, prior to her retirement, continued to encourage and support me beyond all of my expectations. Dr Angela Morgan and Dr Ranjit Khutan became my research supervisors in the last four years of my PhD. Both have encouraged and guided me to the completion of my studies and to a place that I thought that I would never reach; for that, I am eternally grateful.

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CHAPTER ONE: INTRODUCTION TO THE STUDY

1.0 Introduction

The health consequences of female genital mutilation (FGM) during the perinatal period[1] have been highlighted in various studies (Vangen et al., 2002; Berg and Underland, 2013). These may include prolonged labour, perineal lacerations, assisted birth and obstetric haemorrhage. Furthermore, emotional and psychological impacts of the practice have been uncovered where eight out of ten studies identified psychological consequences such as posttraumatic stress and affective disorders (Mulongo, Hollins Martin and McAndrew, 2014).

But the knowledge and understanding of FGM amongst health care professionals who provide care in maternity services, which may impact on the FGM survivor's experience, is under-reported in the literature. Understanding the maternity experiences of women living with FGM could help to understand the level of knowledge and understanding that health care professionals have of FGM. In turn, this could provide a window on the care that is currently provided to FGM survivors. This thesis reports on a qualitative study of the experiences of FGM survivors' access and use of a single maternity service in England as well as the experiences of health care professionals when providing maternity care to women with FGM.

Due to the potential consequences of FGM in perinatal care, it is important that health care professionals who deliver services in England and Wales which FGM survivors

[1] In England and Wales, the perinatal period is defined as the period of time from conception until one year following the birth

access understand the needs of women who have survived FGM in order to plan and implement their care effectively. It is also important that the health care professionals who provide care have knowledge of the needs of FGM survivors in health services such as maternity care (Daley, 2004; Momoh, 2004). To explore midwives' knowledge and understanding of FGM, the Royal College of Midwives' (RCM) conducted a survey[2] of 1,755 midwives' views[3] in England and Wales and identified gaps in midwives' knowledge and understanding of the practice. The results of the survey showed that only 29% (n=242) of midwives were able to identify all types of FGM and 85% (n=847) of midwives were unaware of available resources to support the care of FGM survivors (Stockdate and Fyle, 2012). Furthermore, the survey identified training and education of FGM as a concern amongst midwives; 15.3% (n=215) of midwives had attended training to support the care of FGM survivors and 56.8% (n=786) of midwives expressed the need for further training and education to support the care they provided (Stockdate and Fyle, 2012).

The overall number of midwives surveyed in this report represents only 8.5% of midwives in England and Wales. Therefore it is difficult to generalise these statistics across the entire population of midwives or whether those surveyed were employed in areas where FGM was either in high or low prevalence. Furthermore, there was no data on the cultural dissonance between midwives and FGM survivors or whether this impacted on the care provided. Nevertheless, the survey suggested that FGM training could be inadequate for health care professionals who work in maternity services

[2] The Royal College of Midwives (RCM) (2012) Female Genital Mutilation: Report of a survey on midwives' views and knowledge. London: RCM

[3] Midwives practising in England represented the majority of Midwives surveyed: 82.28% (n=1444)

which may further suggest that the care that FGM survivors receive may be inadequate.

As a professional group, midwives are responsible for the initial assessment of women who access maternity care so that care can be tailored to meet their individual needs (Nursing and Midwifery Council (NMC), 2018). Yet poor knowledge and awareness of FGM can potentially affect the care that women living with FGM receive. Therefore, if knowledge and understanding of FGM is minimal, women living with FGM may not have care that is tailored to meet their needs which could potentially and inadvertently lead to care that causes more harm.

1.1 Use of terminology in this thesis

Several terms are used throughout this thesis that require explanation. This section provides explanation and clarification of these terms. However, some of the terms have cultural connotations and cross-cultural meanings. Therefore, section 4.3 (chapter four) presents these cross-cultural interpretations.

1.1.1 Female Genital Mutilation (FGM)

At the planning stage of this study, careful consideration of the use of terminology was required due to some groups such as the Bondo Society and other pro- FGM campaign groups not recognising or associating with some western-constructed terms (Kavanagh et al., 2012). For instance, a community pressure group, known as African Women Are Free to Choose (AWA-FC) consider the term female genital mutilation, as well as the acronym FGM, as an offensive way to describe a practice that has important

and deep-rooted cultural meaning (Ahmadu, 2009). AWA-FC suggest using the term female genital surgeries, and the acronym FGS to describe the practice (Abdulcadir et al., 2012).

From both a historical and contemporary perspective, there have been a number of terms that have been identified which are used to describe the practice; these include female circumcision, female genital cutting, female genital alteration, female genital modification (Dorkenoo et al., 2007; UNICEF, 2016; United Nations Population Fund (UNFPA), 2018) and female genital surgeries (Ahmadu, 2009; Abdulcadir et al., 2012). Nevertheless, the acronym FGM is the most widely known term for the practice in western society. Furthermore, the World Health Organisation (WHO, 1995) pointed out that the term female genital mutilation describes the inequality of the women within the communities where this is practised due to FGM reportedly being a practice used to control the sexuality of women. For instance, Karanja (2003) pointed out that FGM is practiced to enhance marriageability as practising type III FGM forms a seal over the vaginal orifice and thus preventing sexual activity; a description of the varying types of FGM is located in section 1.2. Karanja (2003) described the FGM 'victims' as being voiceless children who are an objectification of men's mistreatment of females resulting from 'cultural blinding' of the practice of FGM. Therefore, there was a suggestion that this interpretation of FGM contains elements of patriarchy and sexism as well as power and control. Due to this research being conducted in the UK and its recommendations being potentially addressed in the UK, it was concluded that using the term female genital mutilation and the acronym FGM was the most comprehensible way to express the practice in this thesis.

1.1.2 FGM Survivor

There was an acknowledgement that referring to women as victims of FGM may add a dimension of negativity in that it portrays all women in this group as vulnerable. For instance, guidelines such as the WHO (2018) and the Royal College of Obstetricians and Gynaecologists (RCOG), (2015) portray women as victims. Yet, Ewers (2014) pointed out that women who have spoken out about their experiences of FGM have described their agency as survivor. Equally, women who have published their experiences have referred to themselves as 'survivors' (Dirie, 1997; Wardere, 2016) which led to the term being adopted for this study. Therefore, the terms FGM survivor or women having experienced FGM are used throughout this thesis.

1.1.3 Vulnerability and vulnerable

The term 'vulnerability' is used throughout this thesis, therefore requires clarification of the use of the term in this section. Hawker (2006) defines vulnerability as being exposed to the potential of harm from attack; either physically or emotionally. Equally, the term 'vulnerable' is an important term in this study. Hawker (2006) further defines the term vulnerable as a person, or group of people, who are in need of support, specialist care and/or at risk of neglect and/or abuse. In line with the terms silence and silent, there is a symbiosis between vulnerabilities and vulnerableness that are described during this thesis where support is required as well as specialist care.

Furthermore, describing FGM survivors as 'victims' alludes to vulnerability and/or vulnerableness; particularly when services provided for FGM survivors exist within 'vulnerable women services' as recommended by RCOG (2015) and WHO (2018). Yet

there are further nuances of vulnerability and vulnerableness that exist outside of the provision of health services. This was explored during this study.

1.2 Description of FGM

The most recent definition states that FGM is all procedures that involve partial or total removal of the external female genitalia, or any other injury to the female genital organs for non-medical reasons (WHO, 2018). In addition, the WHO's original classification of FGM into four distinct groups was extended to include sub-types within these groups to provide a clearer variation within each type. Figure 1 illustrates the typology of FGM.

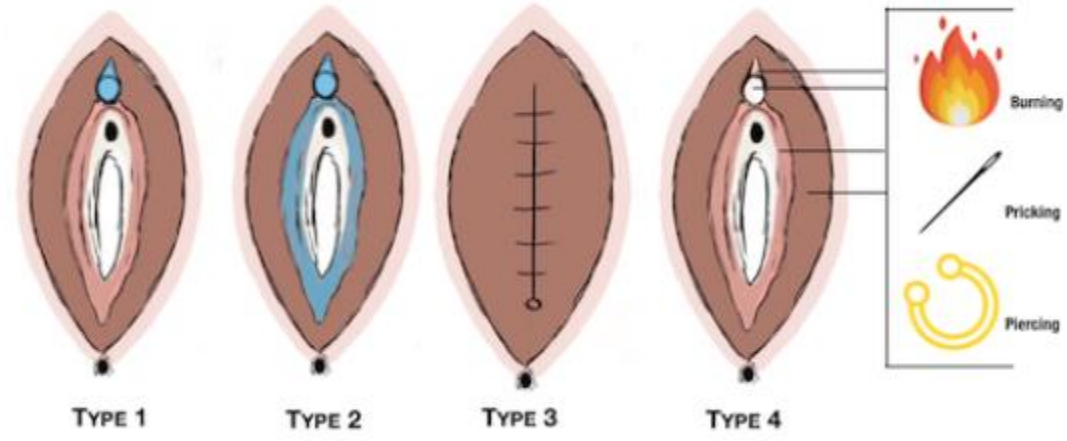

Figure 1: Types of FGM. Barnardo's National FGM Centre (2018)

Type I (cliteroidectomy)

Type I FGM describes the partial or total removal of the clitoris and the surrounding prepuce. Type I FGM is further sub-divided into Ia and Ib.

- Ia is the removal of the prepuce or clitoral hood
- Ib is the removal of the prepuce as well as removal of part or all of the clitoris

Type II FGM (excision)

Type II FGM describes the partial or total removal of the labia minora and in some cases, includes removal of the clitoris. These types are sub-divided into types IIa to IIc

- IIa is the removal of the labia minora only
- IIb is the partial or total removal of the clitoris and labia minora
- IIc is the partial or total removal of the clitoris, the labia minora but can include partial removal of the labia majora

Type III FGM (infibulation)

Type III FGM describes the removal of the labia minora and partial or total removal of the labia majora. The remaining tissue is then stitched together to create a seal over the vaginal orifice. In many cases, the clitoris is left intact beneath the scar tissue that covers the vaginal opening (Andro et al., 2016). Type III is further sub-divided into types IIIa and IIIb.

- IIIa is removal and apposition of the labia minora
- IIIb is removal and apposition of the labia majora.

Type IV FGM

Type IV FGM encompasses all other practices that involve any kind of alteration or injury to the female genitalia (Rashid, Mohammed and Rashid, 2007). This includes pricking or piercing the clitoris or the labia minora, in some cases, it can include both of these (Rashid, Mohammed and Rashid, 2007). Other practices include performing cuts inside the vagina to produce scar tissue to narrow the vaginal canal; these are known as gishiri or anguria cuts as well as practices that include stretching the labia. However, it is noted that there is a growing culture of genital piercing in western society

and therefore questions whether women who choose genital piercing are treated differently according to their ethnic origin. Equally, it should be considered that FGM is usually performed by lay people and as such, it is probable that they do not conform to performing a specific 'type' of FGM. Consequently, it may be problematic to differentiate between specific types in some women.

With the increased prevalence of FGM in contemporary UK society further definitions have emerged, but from a social and political perspective. However, these definitions appear to be subjective views rather than actual definitions. Hosken (1979), a pivotal voice in western society's interpretation of FGM, described FGM as a brutal act of child abuse which aims to control the sexuality and sexual reproduction rights of women. RCOG (2015) defined FGM as a human rights violation and a form of child abuse and the RCM, RCN, RCOG, Equality Now (2013) issued joint recommendations on 'Tackling FGM in the UK' which defined the practice as a severe form of violence against women and girls. All of these definitions have been conceived by outsiders of the practice, so to provide a balanced view, definitions from insiders of the practice will also be considered in this thesis.

1.3 Reasons and rationale for FGM

In order to provide some context of the needs of women and why their voices may not be heard when accessing maternity services in England and Wales, it is useful to understand the possible rationales given for the practice of FGM. Rationales given for FGM may uncover truth and/or beliefs surrounding the practice which may contribute to the ontological and epistemological perspectives inherent to this study. Since the

publication of the Hosken Report in 1979, there have been a number of reasons given for the practice of FGM. These reasons have attempted to rationalise the practice and identify common themes. The most common perceived reasons for the practice include religion, culture and tradition, socio-economic and aesthetic reasons (Burrage, 2015); with religion, culture and tradition being the most frequently used rationales for FGM. Whilst it is overwhelmingly argued in western society literature that there is no religious connotation for practising FGM (Hosken, 1979; Burrage, 2012), Abdi (2007) uncovered a strong belief in a religious connotation with FGM. This suggests that while it may not be specifically indicated in religious text, communities may interpret meanings from religion which are believed as 'truth'. This is further explored in chapter three.

1.4 Background to the study

From a young age my mother was influential in shaping my beliefs; in particular, around culture and how important it is in shaping our experiences, as well as how this influences how health professionals work with different populations. She worked in social care during the 1980s, and during that time worked in a particularly deprived area of Birmingham. This area was very diverse in terms of ethnicity and socio-economic status and had a large BAME[4] community. Through her experiences working to address the social care needs of this community, I was introduced to the challenges that impact upon these communities and was taught to recognise the value of cultural diversity and the importance of working in a non-judgemental manner. This was further enhanced through my professional training as a midwife, and subsequently my experiences in midwifery practice.

[4] Black, Asian and Minority Ethnic (BAME)

My midwifery training, and policy and education that is integral to health care, is that FGM survivors are essentially victims or perpetrators. This is a core message within FGM awareness training that is available to health care professionals as identified in section 4.6. I acknowledge that there was potential for ethnocentrism due to my professional status, as well as my position as an outsider to the research. Therefore on reflection, it was imperative to be open and reflexive in identifying and exploring 'silences' within the literature of the FGM survivors and health care professionals and how each group of participants were situated in the research. It was equally crucial to recognise my relationship with participants, as well as my situatedness to the focus of the study, so that I was able to convey and conceptualise particular 'silences' that are presented later in this study.

As such, during the conception and design of this study, it became important to continually question my motivation for this study and to consider the language used throughout the literature. This was particularly important when analysing the education packages and guidelines that are tools for health care professionals when providing care to FGM survivors; these were a reflection of the care the FGM survivors received as well as the education that I received.

The concept of this study was born during my undergraduate midwifery programme where I was introduced to FGM. My initial reaction to this was shock, disbelief and anger. On reflection, I realise that this was due to the perspective of FGM in western society which was presented in all available education of the practice. However, this initial introduction to FGM led me to find out more about the practice, as well as views

of health care professional colleagues. When I discussed FGM with my peers, they universally condemned the practice as horrific, brutal and abuse. I was met with the same response when I sought the views of senior clinicians.

My first experience of providing care to an FGM survivor was as a student midwife. At the time, FGM was a subject that was rarely discussed; it had only been a little over one year since the FGM Act (2003)[5] had come into force. FGM awareness training was seldom available to health care professionals and guidelines and/or recommendations of providing care to FGM survivors was almost non-existent. I approached senior clinicians to ask their advice on providing care to the woman, but they had little knowledge of FGM and none could give me any advice on providing care.

Although I had received a basic awareness of FGM as part of my midwifery education, I realised that it did not seem to reflect the fear that I witnessed in this woman. My recollection of the sheer fear that the woman exhibited remains as vivid today as the day I met her. As a result of this experience, I sought every opportunity to care for FGM survivors to identify whether other FGM survivors exhibited similar reactions to their experience of maternity care. Unfortunately, all subsequent FGM survivors that I cared for displayed the same fear on admission to maternity services; however, this fear was profound and appeared to be far more intense than any other woman who was admitted into the maternity services. When caring for these women, and talking through their fears, expectations and experiences, I felt that knowledge in western

[5] The Female Genital Mutilation Act (2003) came into force on 3rd March 2004.

society around FGM lacked understanding of the experiences of the women in maternity services.

When I qualified as a midwife, I began providing awareness training to midwives and other health care professionals on caring for FGM survivors. In parallel, the media and politicians became interested in FGM following a six-year initiative by the Trust for London which aimed to tackle FGM in the UK (Brown and Porter, 2016). The focus became eradication of FGM through education. But the first multi-agency guideline for England and Wales was heavily threaded with victim-perpetrator agency which was directed at FGM survivors (HM Government, 2011). The victim-perpetrator theme was continued and enhanced through a summit (known as the Girl Summit) co-hosted by the UK coalition government and The United Nations Children's Fund (UNICEF) in 2014. The Girl Summit introduced mandatory reporting of FGM in under-18s as well as FGM protection orders, collecting data on FGM survivors in England and Wales and changes to legislation. Yet through all of these changes, the voice of the FGM survivor appeared to be absent.

Since my first experience of caring for an FGM survivor, there has been a perpetual absence of the survivor voices on experiences of maternity care; including their opinions of the many changes to care that they will have experienced following the introduction of various recommendations and legislation. Nevertheless, no caution was exercised in the implementation of these changes which had the potential to further marginalise an already marginalised group of women. When discussing these

personal concerns with my peers, I felt that I was a lone voice in my concern for the effect that these changes may have on the experience of care for FGM survivors.

Hence, in view of these potential experiences and the changes to care, the concept of this study was born. Whilst I initially sought to understand health care professionals' knowledge and understanding of FGM, I reflected that it was important to seek FGM survivors' opinions and views of their experience of maternity care. My rationale for seeking these views was to appreciate how (or whether) care can be improved to meet their needs and to address any fears that FGM survivors may have when accessing maternity services.

Yet I also acknowledged that cognitive and cultural dissonance played a significant role in my relationship with FGM survivors. But this may have been reflective of the education on FGM that I had received in my midwifery training as well as my cultural heritage being rooted in western society ideology. Nevertheless I had very little cultural knowledge of FGM and cultural understanding of FGM survivors' experiences of maternity care, so the only way I could reduce my dissonance was to learn from the FGM survivors themselves. As such, reflexivity became central to my learning experience with FGM survivors.

Furthermore since the study focused on maternity service experiences, I acknowledge that I am viewing the issues in this study through a particular lens. Bias in research is a term that is used which refers to the influence in a study which might distort the results (Polit and Beck, 2018). However, bias is most commonly associated with

quantitative studies and since qualitative research involves the researcher collecting qualitative data from participants and analysing such data, there is always an element of subjectivity in the findings. Whilst reflexivity and reflection on the study (and findings) can help readers to understand the potential elements of bias in qualitative research, the researcher plays a key role in the qualitative enquiry. Thus separating bias from such studies is neither possible nor desirable since it provides a window to the researcher's interpretation of the data (Galdas, 2017). Furthermore, reflection and reflexivity can aid in transparency of the researcher's decisions in interpretation.

My hope is that the research reported in this thesis will contribute to improving care for FGM survivors, improving the knowledge of health care professionals and limiting fear that I witnessed when I first encountered an FGM survivor in maternity care.

1.5. Wider context

Towards the end of the twentieth Century, some FGM survivors, as well as researchers, described their first-hand accounts of the practice of FGM in the global political and media arena. Hosken (1979), whose interpretation of FGM is seminal in the understanding and knowledge of FGM in western society, provided an outsider perspective of FGM that was discovered by chance whilst conducting research on the urban and economic development of women in sub-Saharan Africa. The Hosken Report provided detailed accounts of direct observation and interpretation of the practice of traditional female circumcision and the rituals surrounding the practice which Hosken concluded to be genital and sexual mutilation of women and girls (Hosken, 1979). In an examination of Hosken's report, Hay (2012) noted that Hosken

wrote from a white feminist perspective and based the conclusions on the intrinsic westernised values of society and culture without fully understanding the traditions surrounding the practice. Hay (2012) also concluded that the Hosken Report portrays a subjective, and often demeaning, opinion of the people who practised FGM, which in contemporary research, gives little value to the findings from the study. The interpretation of FGM in the Hosken Report remains a key feature of contemporary FGM research so is discussed in further detail in relation to the suggestion of paternalism and sexism in chapter four as well as being compared to contemporary research of FGM.

Since the Hosken Report, the WHO has sought to promote international abandonment of the practice (Hehir, 2015). National and international governments[6], organisations, charities[7] and individuals[8] have strived to raise awareness of the practice with an overall aim to end the practice globally (UNICEF, 2016). Table 1:1 provides an overview of several countries that have enacted statute to prohibit the practice of FGM. However, in many of these countries, FGM is an intrinsic element of cultural heritage and illegality of the practice has achieved very little in terms of halting the practice in these countries (UNICEF, 2016). Equally, the majority of the available research is based on the experience of health care professionals' service provision for FGM survivors. This includes the complexities around planning and provision of care in

[6] Governments of countries that have pledged to end FGM include the United Kingdom, the United States of America, France, Germany, Australia, Nigeria, Egypt, Eritrea

[7] Organisations and charities that are striving to end FGM include 28TooMany, UNICEF, UNFPA and the World Health Organisation

[8] Two most recognised individuals who have published their experience of FGM in autobiographies are Waris Dirie (1998) and Hibo Wardere (2016)

maternity services but not the experience of that care from the perspective of FGM survivors themselves.

1.6 Global Prevalence

FGM is most prominent on the African continent, the Middle East and South East Asia (Sipsma et al., 2012). UNICEF (2016) reported that at least 30 African countries practice FGM with varying prevalence rates across these countries. Costello (2015) pointed out that statistical data surrounding FGM prevalence is often challenging due to difficulties in accuracy of the data. For instance, in countries where FGM is most prevalent, communities may live in nomadic tribes, as described by Dirie (1998) and as such may be difficult to locate in vast desert regions.

However 28TooMany (2018), a non-profit organisation working across Africa, have provided some country-wide statistics of prevalence across continental Africa and some Middle-East countries. Although Costello (2015) questions the reliability of such statistics, these can be a useful starting point to organisations that provide care for women who originate from these countries to identify the probability of whether the woman is an FGM survivor. Chart 1 illustrates some country-wide prevalence data for 15-49 year old girls and women (28TooMany, 2018). Whilst there are over 30 countries that appear to practice some form of FGM, the chart represents countries where FGM prevalence is greater than 65%. Despite national and international efforts, UNICEF (2016) statistical evidence suggests that the practice has not declined and estimates that there are 200 million FGM survivors globally. Nevertheless, it can be argued that the identified increase in prevalence may be due to improvements in recognition of FGM rather than an increase in the practice.

Table 1:1 FGM prevalence in Africa (UNFPA and UNICEF, 2016)

Country	Year FGM was banned	Prevalence of FGM prior to ban (% of population)	Statistical evidence of FGM (% of Population)*
Benin	2003	16.8%	12.9%
Burkina Faso	1996	81%	76%
Central African Republic	1996, 2006	25%	17.9%
Chad	2003	38.4%	44%
Cote d'Ivoire	1998	46.9%	38%
Djibouti	1994, 2009	93.1%	93%
Egypt	2008	97%	87%
Eritrea	2007	88.7%	83%
Ethiopia	2004	73%	57%
Ghana	1994, 2007	5.4%	3.8%
Guinea	1965, 2000	96.4%	46%
Guinea Bissau	2011	50%	45%
Kenya	2001, 2011	27.1%	21%
Mauritania	2005	72.2%	69%
Niger	2003	5.8%	2%
Nigeria	Federal ban 2015	50%	25%
Senegal	1999	88%	25%
South Africa	2000	1.8%	No data available
Sudan	2009	90%	87%
Uganda	2010	50%	1%

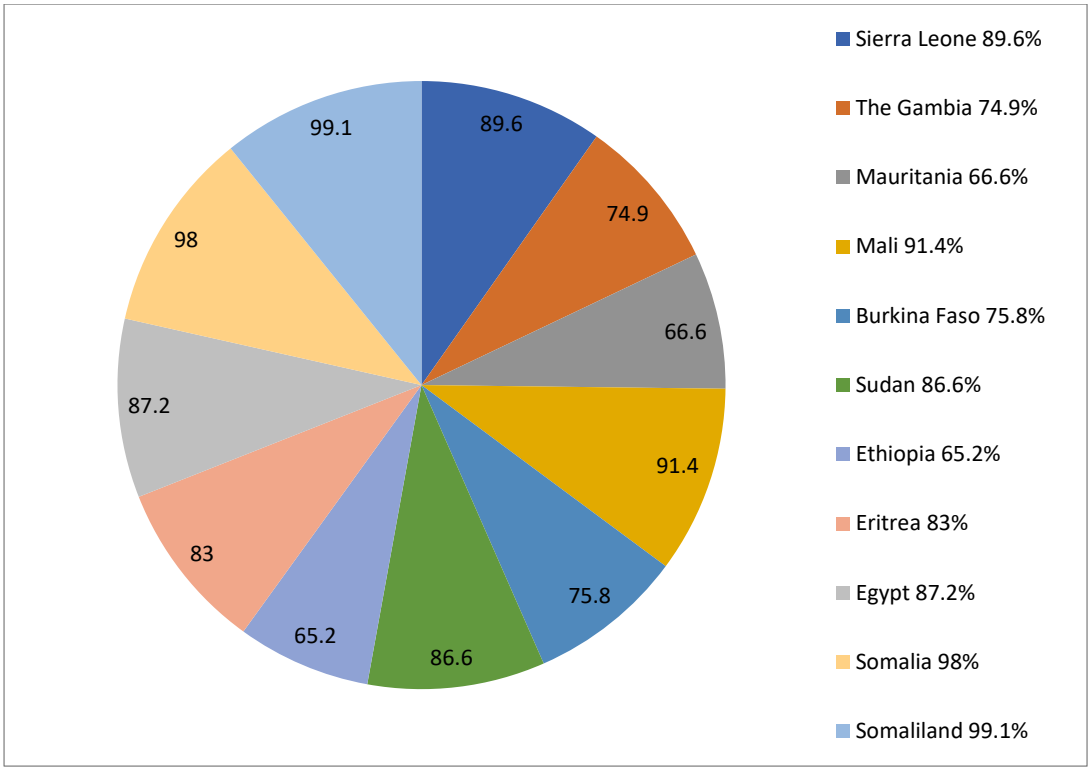

Chart 1: International Statistics of FGM (28TooMany, 2018)

1.7 Prevalence of FGM in England and Wales

There have been several reports on the prevalence of FGM in England and Wales. The City University London and Equality Now published an interim report estimating that 137,000 women of childbearing age who were survivors of FGM were living in England and Wales (Macfarlane and Dorkenoo, 2014). These findings were based on census records from 2001 to 2011 and countries of origin of the women and girls. Women and girls who had migrated to England and Wales from African countries that practice FGM were all considered to be FGM survivors or at risk of FGM (Macfarlane and Dorkenoo, 2014). Yet these statistics were estimates rather than accurate numbers so it is conceivable that the number of FGM survivors in England and Wales could be substantially higher or substantially lower.

As a result of the Macfarlane and Dorkenoo interim report, the UK coalition government pledged to end the practice within a generation and, in 2014, hosted the Girl Summit in partnership with UNICEF in the UK. However, there was no indication at the time of the Girl Summit of the actual prevalence of FGM in the UK, how the end of the practice would be achieved or whose generation the practice would end with. Following the Girl Summit, a national FGM prevention programme was launched with the aim of education and eradication of FGM; an element of the programme included the commencement of data collection, instead of relying on statistical data from census records, to ascertain accurate statistics of FGM survivors in the UK (Department of Health, 2014). The Health and Social Care Information Centre (HSCIC) began to collect this data from NHS organisations in England and Wales to improve the prevalence data (Knighton, 2015). The remit of this was to gain an understanding of the prevalence of FGM in England and Wales which may aid the planning of services for FGM survivors as well as providing a platform of information for other services (Knighton, 2015).

At the time, prevalence of FGM in England and Wales was unknown therefore it may have been pertinent to launch the data collection programme prior to the prevention programme in order to understand the true extent of FGM in England and Wales. Furthermore, the UK coalition government's pledge to end FGM is extremely challenging without an understanding of the concept and philosophy that is intrinsic to the practice.

Chart 2 illustrates data collected by NHS Digital which identified an increase in the prevalence of FGM in England from 6,763 in 2014-15 to 9,490 in 2017-18 (NHS England and Brownjohn, 2018)

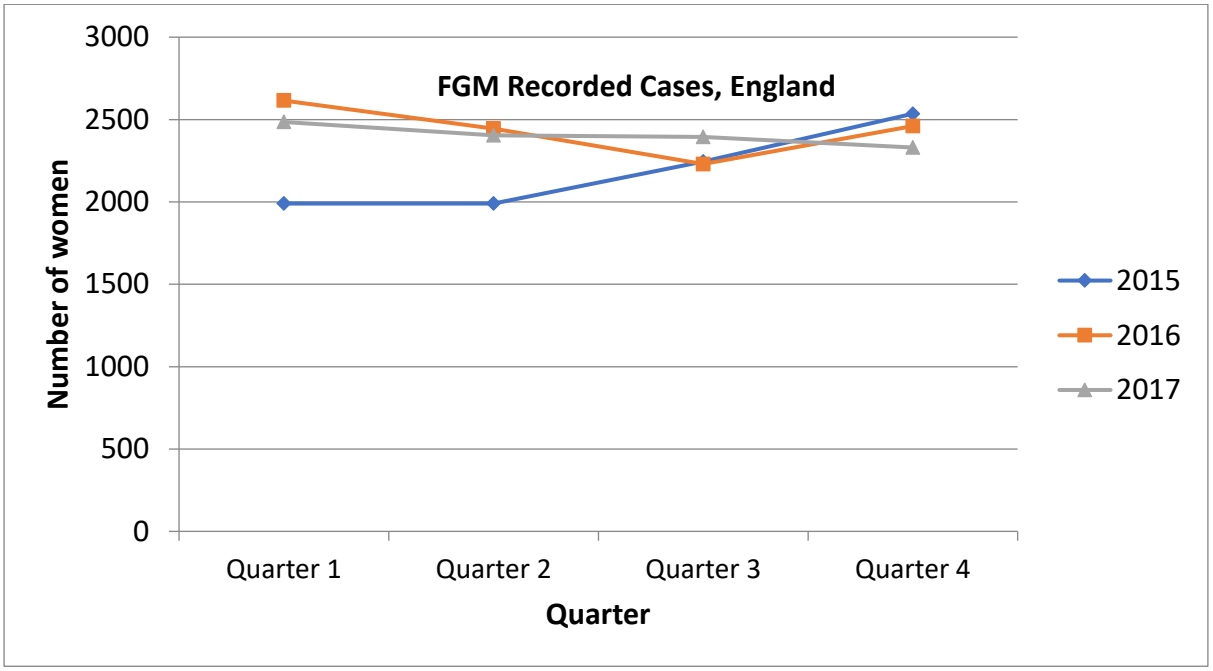

Chart 2: NHS Recorded Cases in England. Data Source: HSCIC (2016); NHS Digital (2017); NHS Digital (2018)

Chart 2 highlights the number of recorded cases by quarter; in the year 2017-18, there were a total of 9,490 recorded new attendances in various NHS services in England where FGM, or a procedure relating to FGM, was identified (NHS Digital, 2018). Yet the Office for National Statistics (ONS, 2018) reported approximately 145,000 women of childbearing age who were resident in England who had originated from countries where FGM is widely practiced. Though, this figure does not include women and girls who are residing in England temporarily as well as asylum seekers or those who have entered England unlawfully.

Nevertheless, the statistical data collected thus far is experimental and relies upon each NHS organisation's accuracy with data submission (NHS Digital, 2018). As illustrated in Chart 2 the most recent report suggests that FGM is in decline in quarter four of 2017 but the statement on the validity of the data collected thus far does not provide assurance that this data is reliable (NHS Digital, 2018).

Furthermore, due to the data being collected predominately by NHS services, it is not possible to determine the number of women who have experienced FGM but who have not sought contact with health and social care services in England. As a result, it is impossible to determine whether FGM is in decline in the UK. However, it can be argued that this has provided some context of an approximate number of women who have accessed maternity services in order to plan care requirements and services to meet FGM survivors' needs.

1.8. First-hand accounts of FGM

There have been several first-hand accounts of experiencing the practice which have led to studies of health care professionals' understanding of FGM. The two notable individual FGM survivors whose experiences have been published in autobiographies are Dirie (1998) and Wardere (2016). One of the most prominent was a 1997 interview with Waris Dirie by Marie Clare magazine[9] which brought FGM to the attention of the wider public. Dirie expanded on the interview and provided an in-depth account of her experiences of FGM in her autobiography, Desert Flower. Dirie (1998) provided insight

[9] Marie Clare magazine is a popular magazine that is aimed at women by publishing health issues and management, global issues, beauty advice and fashion topics.

into her early life as living amongst a nomadic tribe who travelled around the Somali desert to meet their needs for food and water. Dirie (1998) described a happy childhood with a close relationship to her parents and siblings. She described FGM as being shrouded in secrecy amongst her tribe but had an abstract awareness of this signifying the process of transition to womanhood (Dirie, 1998). She described her anxiety at witnessing her older sister's FGM and the effect that this had on them both. Yet Dirie (1998) described the reactions from the older members of the tribe to young girls who had not experienced FGM; they were often referred to as 'dirty' and 'unsanitary'. Dirie (1998) described having romantic feelings for an older boy in the tribe and requested that her mother arrange for her FGM procedure so that she would receive the same attention from him as he gave to her older sister who had undergone FGM; at the time, Dirie was five years old. Dirie (1998) described feelings of excitement prior to meeting the woman who performed FGM, known as the cutter, but realised that she would experience the same procedure that she witnessed her sister undergo. Dirie (1998) described the cutter using her saliva to clean dried blood from a broken razor blade prior to performing FGM on her. She further described being held against her mother's body and how her mother blindfolded her. Dirie (1998) recalls that she did not protest during the procedure, as she wanted her mother to be proud of her but also described how she lost consciousness towards the end of the procedure. Although her mother participated in her FGM, Dirie blamed the cutter for this experience; referring to her as the 'killer woman'.

Hibo Wardere is another Somalian FGM survivor who provided insight into her FGM in an autobiography entitled *Cut*. Wardere (2016) described her experience of FGM at six years old in similar circumstances to Dirie, but the intense suffering that she

experienced is further explored. Wardere (2016) described being held down by her aunts with her mother present at the time. Despite Wardere repeatedly calling for her mother's help, her mother responded to the cutter's request to keep Wardere quiet. Wardere (2016) described the breakdown of the relationship with her mother from this point due to blaming her mother for her FGM. Both Dirie and Wardere described the reasons given to them for their FGM as proof of virginity and a practice that all their female predecessors had experienced. Both women left Somalia during their teenage years. Dirie (1998) described leaving Somalia to escape a forced marriage to a man who was approximately 40 years older than her, whereas Wardere (2016) described leaving Somalia with her family, without her father, due to the danger from the war that took place in Somalia at the time. Both of these accounts are deeply personal and several media reports had expressed profound outrage[10] in response to these accounts, as well as an inability to comprehend that FGM is a reality for women and girls worldwide. Both women have used their experiences of FGM to raise awareness of the practice in global anti-FGM campaigns.

Nevertheless, in contrast to this notion is the perspective of the movement African Women Are Free to Choose (AWA-FC) who describe their agency in relation to the practice of FGM (Ahmadu, 2009). The group rejects the notion that FGM is harmful but is an intrinsic element to the initiation into adulthood. Nussbaum (2001) described a philosophical stance regarding agency and victimhood which provides insight into AWA-FC's position regarding the practice of FGM; this is further expanded by the Sierra Leone Women Are Free to Choose (SLWAFC) movement which was founded

[10] London Evening Standard 30th April 2013, The Spectator 24th September 2016 and the Guardian 7th March 2018 all express stories of FGM occurring in the UK and worldwide.

with the same principles of AWA-FC. The founding philosophy of both of these community-based organisations was that it is a woman's human right to choose circumcision[11]. The principles of the culture surrounding this is based on an element of article 27 (1) of the Universal Declaration of Human Rights which states that everyone has the right to freely participate in the cultural life of the community (UN Assembly, 1948). Equally, both organisations believe that FGM should not be performed on children who are deemed unable to provide informed consent. Yet, neither organisation actively condemns FGM for children since the Bondo rituals are usually performed around the time of puberty. In addition, both organisations were founded by a prominent member of the Bondo Society of Sierra Leone. The Bondo Society is a secret, all-female organisation active in West Africa, most prominent in Sierra Leone, who practice initiation ceremonies into adulthood; central to their initiation process is FGM (FORWARD, 2017).

Nevertheless, the majority of FGM procedures are performed on individuals who are below the age of 18; with the majority of these being children below the age of 10 who do not have the capacity to consent to such a procedure due to their age. The AWA-FC further rejects the term FGM and the description female genital mutilation due to the negative connotations such as women being described as victims who have been brutally mutilated (Ahmadu, 2009). Yet many women who have experienced FGM, including those whose experiences were described in this section, agree with the sentiment of the WHO in that the term is parallel to the harm that the practice causes. Moreover, the women who have experienced this believe that they have survived FGM rather than have been victim to this. Karanja (2003) describes FGM survivors as

[11] 'Circumcision' is used in this sentence due to both groups rejecting the term FGM.

women who have regained or retained their voice and are able to speak out for themselves as well as the voiceless. Therefore, due to this research only including women over the age of 18, the women are referred to as either having experienced FGM or FGM survivors in an attempt to alleviate the negative connotation that the use of the term FGM may contribute to.

1.9 Study justification

There are a number of key justifications for this study each of which are addressed in turn here. Since the Girl Summit there have been several changes to both policy and law regarding FGM across England and Wales; for instance, section 74 of the Serious Crimes Act (2015) amended section 5B of the FGM Act (2003) (HM Government, 2003) to include mandatory reporting of FGM. The FGM Act (2003) (HM Government, 2015) are discussed in further detail in chapter four. As mentioned earlier, collecting data on FGM survivors was also introduced at this time which resulted in increased input from health care professionals in particular. Therefore the education of all health care professionals is important so that they are able to identify women who may be FGM survivors and provide the care that will meet their needs. However, current education around FGM predominately features the legal aspects related to FGM with very little cultural awareness of the practice which can create cultural dissonance in health care. As a result care that is provided, particularly by maternity services, is threaded with the legal aspects of FGM with no cultural sensitivity. This is discussed in detail in chapters three and four.

Section 1.7 highlighted the increase in FGM survivors within England and Wales (Macfarlane and Dorkenoo, 2014) and the statistics which report the approximate number of women and girls in England and Wales. Therefore, it is important that all professionals who are involved with providing care to women who are FGM survivors have a better understanding of the practice and how to best care for FGM survivors. Equally, whilst NHS Digital's data is useful in identifying nominal statistics of women accessing services, none of the data is sufficiently rich to provide any context to the care that was needed, or the experience of care that the women received. For example, there is no data regarding the number of women who required counselling or further psychological care due to their experiences with FGM and there was no data regarding any procedures required for women with FGM type three to open their vagina for the purpose of medical examination or childbirth.

Furthermore, there is a lack of empirical studies involving FGM survivors, particularly in relation to maternity care experiences. Whilst it is useful to understand health care professionals' experience of providing care (Whitehorn et al., 2002; Harris, et al., 2002; Braddy and Files, 2007; Simpson et al., 2012) the foundations of care needs should be understood from the perspective of FGM survivors. Without an understanding from the FGM survivor, there is no foundation upon which to improve care or to improve the education of the health care professional on the practice of FGM. The National Institute of Health and Care Excellence (NICE) recommends providing care tailored to meet individual needs and being aware of the patient as an individual; this should include the patient's cultural needs (NICE, 2012). Yet thus far, studies have not sought the opinions of FGM survivors on the care they receive in maternity services. It is hoped that the outcome of this study will provide information from the perspective of FGM

survivors on their experience of maternity care as well as the experience of health care professionals in providing care to FGM survivors. It is also hoped that recommendations may help to shape the care that is provided to FGM survivors and enhance the programme of education for all health care professionals on the subject of FGM.

1.10 Aims and objectives

The overall aims of this research were to qualitatively explore the maternity care experience of women survivors of FGM as well as health care professionals' experiences of providing such care. This was addressed via the following objectives:

- Explore the experience of FGM survivors in a maternity service in England
- Explore the knowledge and understanding of FGM amongst health care professionals who provide maternity care to FGM survivors
- Critically examine the education and guidance widely available to health care professionals on FGM
- Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally
- Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.

These aims and objectives are further strengthened following the review of literature in chapter four and presented in section 5.1.

1.11 Chapter by chapter synopsis

The chapters within this thesis have been structured around the Sound of Silence framework; henceforth referred to as the 'silences framework'. Serrant-Green (2011) developed the framework for the purpose of research with sensitive subjects within marginalised populations. FGM has been described as a complex and sensitive subject, due to the nature of the phenomenon of FGM and the cultural differences of women who have experienced FGM (NICE, 2018). The recommendations from NICE (2018) include providing maternity care for FGM survivors under the umbrella of vulnerable women services.

The silences framework has since been used to provide a framework for research of offender rehabilitation (Eshareturi and Serrant, 2018) and hip fragility in the under 60s (Janes, Serrant and Sque, 2018). However, the framework has not yet been used to articulate an area researched within maternity services. Therefore, this study has explored the use of the silences framework within a marginalised group of women accessing maternity services.

- Chapter one presents the introduction, background and outline of the study. This includes the identified problem, the aims and objectives of the study and the outline of the chapters.
- Chapter two presents the ontological and epistemological perspectives inherent to the study as well as the framework used to provide structure to the research reported herein.
- Chapter three provides a historical overview of FGM which offers some context to various rationales for the practice.

- Chapter four marks stage one of the silences framework by contextualising the historical and contemporary realities of FGM for both survivors and health care professionals. Language and terminology are critically analysed as well as guidelines and education used to underpin the care provided to FGM survivors.
- Chapter five marks stage two of the silences framework which presents the methodological approach inherent to this study as well as the methods used to collect and analyse the data. Chapter five also includes the ethical considerations for this study as well as potential and actual risks and actions to mitigate against these.
- Chapter six presents phases one to three of the analysis in stage three of the silences framework.
- Chapter seven presents phase four of stage three of the silences framework which provides a final researcher review and analysis of discourses.
- Chapter eight presents stage four of the silences framework and the discussion of the findings from the phases of analysis. In conjunction with the findings from the literature review, the discussion uncovers the gaps in knowledge which are presented in chapter nine.
- Chapter nine presents the conclusion which consists of the unique contribution to knowledge as a result of the research, evaluation of the problems encountered during the study as well as the reliability of the findings and the limitations. This chapter also presents a researcher reflection on the use of the silences framework for this study and concludes with stage five of the silences framework which consists of the recommendations identified from the collected data.

1.12 Chapter summary

This chapter has presented the background to the study which encompasses the background of the researcher. The use of terminology surrounding FGM as well as the reasons and rationale for the practice has been presented. There has been an outline of the wider context to the study which also included the current global and UK statistics of prevalence rates of FGM. Furthermore, this chapter outlined the justification of the study which highlighted the issues with the current statistical data, the lack of FGM survivor voices in the literature and recommendation for care as well as insufficient cultural understanding in health care education.

The aims and objectives for the study have been presented and a chapter-by-chapter synopsis has provided a brief outline of this thesis. The following chapter will provide the theoretical and philosophical underpinning to the study as well as the framework used to provide structure to the research.

CHAPTER TWO: STUDY PARADIGM AND FRAMEWORK

2.0 Introduction

This chapter describes the philosophical position which was used to support the foundations of this study. As such, this chapter focuses on the ontological and epistemological perspectives inherent to the research herein. Following the discussion on the ontological and epistemological perspectives of this study, a description and discussion of the framework used to structure and underpin the study is provided as well as the alignment with the study paradigm. The chapter will conclude with an overview of the framework stages.

2.1. Ontological perspective

This study explored views and experiences of maternity care. Therefore, there was potential for FGM survivors to provide multiple views and experiences dependent on their individual perceptions. Furthermore, views and experiences of providing maternity care were sought from health care professionals who provided further multiple views and experiences. However, the current reality of FGM survivors' and health care professionals' experiences is not necessarily concrete; it may be further refined over time due to a contemporary growth of knowledge in this area such as psychological effects of FGM as well as the outcomes of this study.

Guba and Lincoln (1994) pointed out that reality becomes more concrete as it is shaped by evolving influences such as political, cultural, economic, ethnic and gender values which are collectively termed as historical realism (*in* Killam, 2013). Killam (2013) further posited that whilst contemporary reality may not be concrete truth, it is

a contemporary reality. Killam (2013) pointed out that this paradigm is sometimes referred to as neo-Marxism or feminism but utilised the term critical theory which is situated in the post-modernism paradigm. However, post-modernism can incorporate both objective and subjective (or interpretative) epistemologies (Killam, 2013). But critical theory encompasses more subjective findings that are influenced by values that are rooted in the ontological stance of historical realism with a particular emphasis on minority groups and oppression (Killam, 2013). While this has some similarities to constructivism, the ontological and epistemological foundations of critical theory are distinctly pertinent to this study in terms of providing care based on political and cultural foundations as well as receiving such care. Equally, feminism is an important aspect of this study.

Feminist theories with polarised realities have emerged from existing knowledge on FGM from both insider and outsider perspectives. For example, two polarised, and pivotal, views of FGM include Hosken's (1979) Eurocentric outsider view[12] and Ahmadu (2009) Afrocentric insider view[13]. Hosken (1979) study of FGM in various African countries posited that FGM resulted in women's oppression and patriarchal control of sexuality and reproduction. However, Hosken's (1979) work was embedded in second-wave feminism which, according to Thompson (2016) marginalised black feminism and treated sexism as the ultimate oppression. As such, Hosken's work is significantly threaded with power and agency. Whereas Ahmadu (2009) stated that western society's attempt at ending FGM is a patriarchal and colonialist effort to control

[12] An outsider view is considered to be the view or opinion of FGM from a person who has not experienced FGM and does not originate from a culture that practices FGM.
[13] An insider view is considered to be the view or opinion of a person who has experienced FGM and/or originates from a culture or country where FGM is practiced.

women’s bodies and sexuality in countries where FGM is prevalent. These important arguments exposed ethnocentric views and opinions which are discussed in detail in chapter three. Hence, although constructivism and social construction may be useful in the research of the phenomena and cultural differences of FGM between African and western culture, the post-modernist aspects of feminism and critical theory are more suited to this particular study in terms of power, patriarchy and discourse between FGM survivors and health care professionals in western maternity care.

Following Hosken's (1979) publication, the drive to heighten awareness of FGM as a brutal and oppressive act served only to cement the essence that women were universally subservient to the oppression of men in the countries that were studied. This may have resulted in a universal western view of FGM. However, according to Mambrol (2018) some feminist writers sought to construct universality of women which was based on their white, western bourgeois reality. Creed (1987) also argued that western representations of cultures are the products of access to power rather than truth and reality. Hence while Hosken (1979) argued from an essentialist feminist perspective, it was threaded with power and agency which may have served to marginalise FGM survivors. Witt (2018) suggested that this may have resulted in their invisibility and subsequent silence.

On the other hand, Ahmadu (2009) argument, although from a feminist perspective, was in contrast to Hosken’s view of FGM. While Ahmadu attempted to provide an anti-essentialist argument, this was based on the ideology of Bondo Society which resulted in an essentialist feminist perspective but polarised from Hosken. Furthermore, it

suggests that it was Ahmadu (2009) view that western society's interpretation of FGM created vulnerability within African countries who practised adult initiation ceremonies; these arguments are discussed further in chapter four. Nevertheless, each reality argued that FGM is a socio-cultural construction; Hosken arguing gender inequality, Ahmadu arguing gender equality. Furthermore, power, patriarchy and discourse between FGM survivors and health care professionals in western maternity care are the core aspects of this study rather than the construction of the culture of FGM itself. As such, individual experiences are central to this study.

Scotland (2012) pointed out that an individual's experiences can shape their reality and as such multiple realities can emerge from similar experiences based on each individual's perception of the experience; this has been evident in some previously published survivor accounts. For instance, in Dirie (1998) experience of FGM, she blamed the cutter for her resulting trauma, despite her mother arranging her FGM and being present during the event. However, Wardere (2016) blamed her mother for the resulting trauma of her FGM experience despite the cutter carrying out the act. While both women experienced FGM, they had different realities regarding the owner of power during their experience of the practice.

Mertens (2005: 18) goes further and posited that reality is socially created which suggests that truth and reality are situated in socio-cultural experiences and beliefs. However, this is only pertinent to FGM survivors and health care professionals' *existing realities* which may evolve as described by Guba and Lincoln (1994). Furthermore, according to Guba and Lincoln (1994) belief is accepted as truth since it is impossible

to establish its actual truthfulness. For instance, in chapter one religion was identified as a rationale for FGM. However, whilst it was argued by Burrage (2015) that FGM is not mandated in any religious texts, Abdi (2007) identified a strong belief of religious requirement for FGM. Therefore two separate realities were uncovered in one rationale of FGM. Ultimately, truth and reality are relative to each individual's belief and/or experience of an event or events which leads to multiple truths and realities. This is also pertinent in this study where truth and knowledge of FGM are dependent on belief and experience from the perspectives of individual FGM survivors and individual health care professionals in the maternity setting. Furthermore, the researcher may have other experiences of FGM that are different from both FGM survivors and health care professionals which may add subjectivity and complexity to the multiple truths and realities of both participant groups. As such, this suggests that anti-essentialism is core to the realities of participants since universal reality does not exist in this study.

However, what is known about FGM and the subsequent experiences of survivors in maternity care is based on clinical outcomes, outsider perceptions and health care professional's experience of providing care. For instance, there is an abundance of literature on the health implications and professional's experience of FGM survivors in maternity care (Berg and Denison, 2012; Berg and Underland, 2013; Iavazzo et al., 2013; Berg et al., 2014; Balfour et al., 2016; Evans et al., 2019), but there is an absence of literature on the FGM survivor's perspective and experience of maternity care. Therefore the perceived reality for FGM survivors is based on outsider perspectives which portray survivors as voiceless, vulnerable and victims of culture. This is further evident in statute, policy and clinical guidance which is critically evaluated in chapter four. Whilst the victim agency may have been a previous reality

for some FGM survivors, such as Dirie (1998) and Wardere (2016), it cannot be assumed that all FGM survivors have postulated a victim agency. Hence, reality is relative to each individual's lived experience and shaped by socio-cultural interaction and beliefs and political influences of policy, clinical guidance and statute.

2.2. Epistemological perspective

The epistemological perspective in this study followed its ontology in that knowledge was created from multiple realities (Guba, 1990). Guba and Lincoln (1994) suggested that from an ontological critical theory perspective, the ontology and epistemology perspectives of critical theory can potentially overlap. However, due to the interpretivist nature of this research, the epistemology considered the connection of the researcher to the participants; Briscoe (2017) described this as the knower (researcher) to the known (participants). But due to the researcher's position and identity, it was plausible that a closer connection to the health care professional participants' realities may have occurred. This may have incorporated cultural dissonance from the beginning of the study where realities from the FGM survivor perspectives may have been misinterpreted or misrepresented by the researcher. This exposed cultural dissonance was an epistemological challenge since the researcher was an outsider to the participant perspective but an insider to the health care professional perspective; with literature and education in western society representing an ethnocentric view of FGM based on western society ideology. Hence reflexivity became central to the interpretation of knowledge and meanings within this study. Jootun et al. (2009) explain that self-awareness, including personal beliefs and potential ethnocentrism, can impact on the topic so it is imperative to attempt to separate personal views from the

study. But according to Darawsheh and Stanley (2014) a reflexive approach may evolve the researcher's opinion during the course of the research.

Exposing the realities and silences within this study required an inductive approach since it was epistemologically feasible to discover multiple realities. However, interpretation of these multiple realities was dependent on the researcher and their relationship with the research and participants. Hammersley and Atkinson (1995) pointed out that when a researcher is situated in a different social world to the participants, it is important to acknowledge that previous knowledge and experiences may contaminate the process and findings (Briscoe, 2013).

Consequently there was significant risk that the views and opinions of the FGM survivors may have been lost (or remained unheard) due to the researcher's insider position with health care professionals but an outsider to FGM survivors. There was significant risk that FGM survivors may have become further marginalised as a result of the research, findings and recommendations. Hence, throughout the research process, it was important to remain self-aware during the design phase through to the completion of this thesis. It became continually important to consider and address pre-conceptions, perspectives and personal beliefs and values of the researcher. Malterud (2001) pointed out that where the researcher fails to identify these, cultural dissonance and ethnocentrism may be introduced.

2.3. Structure: The Sound of Silence Framework

The silences framework was used to underpin and provide structure to the complex ontological perspectives inherent to this study. Although it is important to note at this point that the silences framework was not used as a theoretical framework for this study but is simply the underpinning structure of the research and to guide the study and check its consistency. The rationale for using the framework in this way was to minimise the potential risk of power imbalances between the FGM survivor participants, health care professionals and the researcher within the framework itself; particularly around cultural dissonance and ethnocentrism. As such, the framework has been modified from its original construction to minimise the risk of a power imbalance in the resulting data. This modification is presented in stage three of the silences framework (during the phases of analysis) so that the FGM survivors were able to review and reflect the findings from health care professionals; in the original construction of the framework, the FGM survivors would not have had this opportunity. The detail of the modification is presented in phases two and three of section 2.4.3.

2.3.1 Defining the 'Silence'

Using the silences framework has led to the term silence being used throughout this thesis. As such, this section provides clarity with the use of the terms 'silence' and 'silent'. Silence is defined as the complete absence of sound (Hawker, 2006). However, in the context of this study, silence also encompasses an absence of knowledge and understanding. Serrant-Green (2011) states that silences are experiences that are little understood, rarely researched and/or under-valued. Hence, silence in this study refers to absence of speech as well as knowledge and/or understanding; in the case of this study, absence in the knowledge and understanding

of FGM. Whilst the term silence refers to a general absence of speech, knowledge and/or understanding of FGM, the term ‘silent’ is used to define specific aspects that are combined to create the root, or the conception, of silence. However, once identified, these are no longer a ‘silence’ or are silent; rather these become ‘voiced’ and/or ‘heard’. As such, in this thesis these are expressed as *silences heard* or *silences voiced* to distinguish between what is silent and what is no longer silent.

The silences framework was conceptualised by Serrant-Green (2011) following research of black Caribbean men’s sexual decisions and health behaviours. Serrant-Green (2011) uncovered the concept of identifying areas of research that are deemed to be ‘silenced’ or ‘silent’ due to these being sensitive and/or ‘under-researched’ which rendered the knowledge within these areas as ‘silent’. According to Serrant-Green (2011) the concept of ‘screaming silences’ was born from the silence, or unheard voices, in areas of research that were particular to health and ethnicity. The silences framework utilises perspectives within the post-modernist paradigm which is suited for research with FGM survivors and health care professionals.

2.3.2 Justification for using the Silences Framework

The ontological and epistemological perspectives of this study located it within the post-modernist paradigm. This led to an interpretivist view that the realities of FGM survivors and health care professionals are not necessarily fixed but are influenced by social and political perspectives. Furthermore, perspectives on FGM can be experienced and interpreted individually (Williams and May, 1996) as seen with Ahmadu and Hosken. This is parallel to the concept of the silences framework in that

Serrant-Green (2011) posited that screaming silences are ‘derived from anti-essentialist viewpoints’. However, Serrant-Green (2011) further interpreted ‘screaming silences’ as an artefact of dominant political and societal perspectives which do not, or cannot, hear particular viewpoints in a given society at a particular time. This interpretation is closely aligned to the historical realism perspective that is intrinsic to the ontological perspective of this study, but from an anti-essentialist standpoint as identified by the polarised arguments of Ahmadu and Hosken.

Furthermore, the feminist theory and discourses of this study that was outlined in section 2.1 is equally aligned to the silences framework. Serrant-Green (2011) explains that silences can affect the power balance and equality of those who are perceived as silent; this suggests marginalisation as a result of inequality and/or a power imbalance. This is an important factor when analysing discourse of insider and outsider views of FGM which may already be marginalised or could be at risk of marginalisation as a result of the research. Therefore caution was exercised when theorising or interpreting the silence of specific groups; Witt (2018) argued that identification of marginalised discourse can reflect the interests and position of the researcher. This was an important consideration when adopting the silences framework for this study since the interpretation of silences were by an outsider perspective to FGM, but an insider perspective to maternity care provision. On the other hand, Serrant-Green (2011) may have been closer to the insider perspective of silence when conceptualising the silences framework and thus the silences framework may have been constructed with a foundational insider perspective. Consequently, reflexivity remained core to the research within the framework when considering whether silences existed in either group of participants for this study. Nevertheless, the silences framework provided a

platform to identify any pre-existing subjectivities that the researcher may bring to the research.

Although the silences framework was created to provide structure to research of Afro-Caribbean men's sexual experiences, it has since been used to provide a framework for researching offender rehabilitation (Eshareturi and Serrant, 2018) and hip fractures in the under 60s (Janes, Serrant and Sque, 2018). Both fields are considered to be marginalised groups.

2.4 Stages of the Silences Framework

There are four key components to the silences framework Serrant-Green (2011) which are expressed in stages:

1. Stage one: Working in silences
2. Stage two: Hearing silences
3. Stage three: Voicing silences
4. Stage four: Working with silences

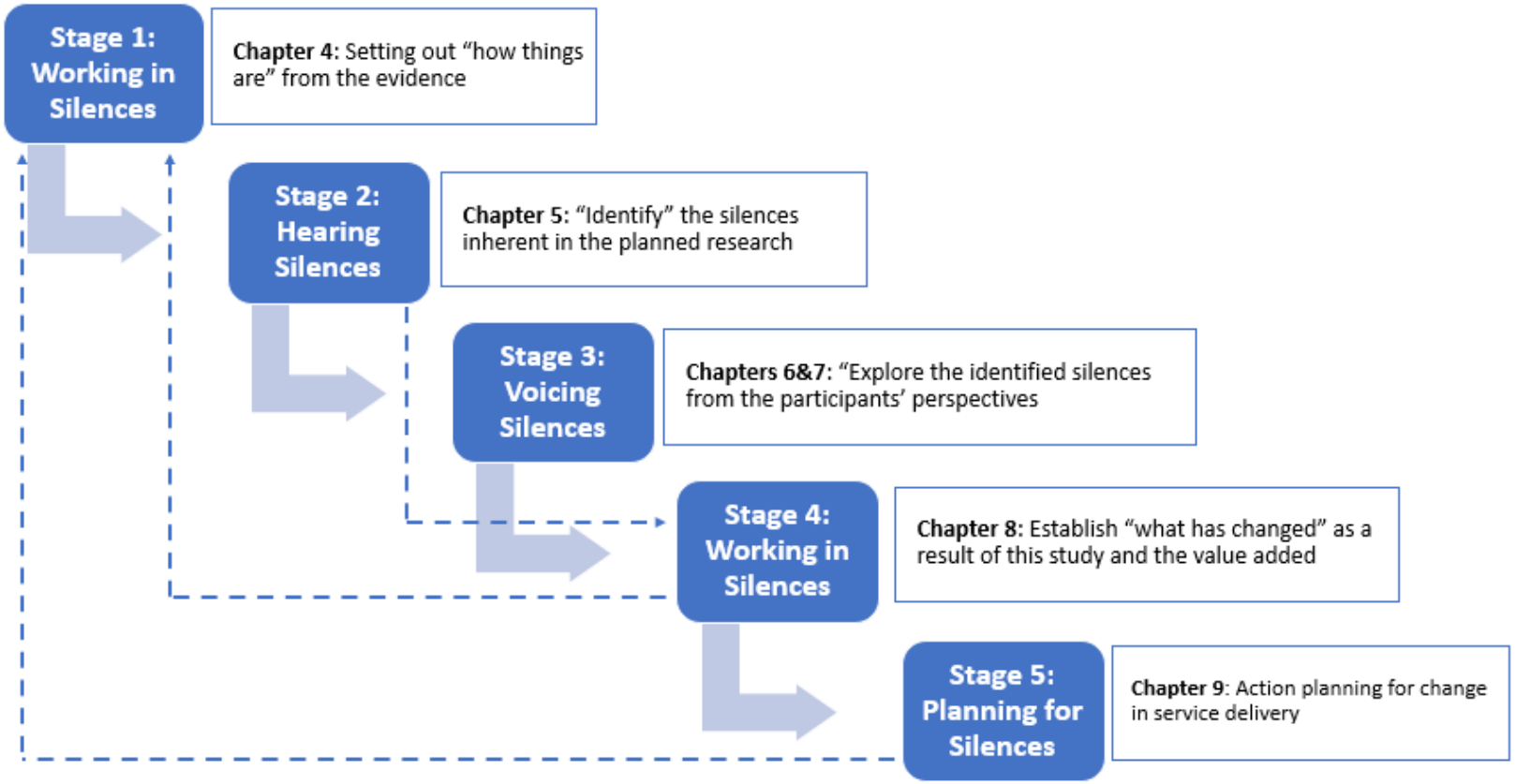

Figure 2: Silences Framework (adapted from Serrant-Green, 2011)

There is an additional stage, stage five, which provides a platform for recommendations in service planning, development and policy change. Due to this study being conducted in a health care setting, stage five is utilised for presenting the recommendations. Figure 2 illustrates an overview of the silences framework which is further described in the following sections.

2.4.1. Silences stage one: Working in silences (Chapter Four)

Serrant-Green (2011) described working in silences as uncovering the facts of the occurrences in contemporary society with regard to the silence. Therefore, this stage was a critical examination of the available existing research and literature of FGM.

There were four key areas in this stage which were fundamental in revealing potential silences around FGM; (i) language and terminology, (ii) legislation, (iii) guidelines and policies, and (iv) outsider and insider views and opinions of FGM. Symbiotic to each of these key areas was a critical analysis of power and discourse central to the literature.

Furthermore, this stage aimed to ascertain preliminary answers to some initial key questions, including what is currently known about FGM and any issues, what appears to be silent within the topic and how things currently are in relation to knowledge and practice. It also establishes the range and scope of the study; for instance within the communities and clinical areas. This stage is therefore vital for helping to ‘expose the real’ world in which the research will take place (Serrant-Green, 2011), which itself facilitates contextual understanding and a basis for the research reported here.

2.4.2. Silences stage two: Hearing silences (Chapter Five)

Stage two of the framework considered the subject matter that is perceived as little understood, valued or researched (Serrant-Green, 2011). Hill et al. (2008) pointed out that when receiving information about a subject, the information can be used to support one's pre–existing beliefs and assumptions. As an outsider of FGM and bound by statutory regulations related to midwifery registration and education, there was significant risk that a power imbalance may have been introduced by the researcher. Furthermore, due to cultural dissonance between the researcher and the FGM survivors, there was a risk of ethnocentrism which may have also become an issue during the phases of analysis; particularly phase two where health care professionals reflected on the outcomes of phase one. Therefore, it was crucial to devise a methodology that would incorporate reflection and facilitate hearing that which was proposed to be unheard and/or not listened to.

2.4.3. Silences stage three: Voicing silences (Chapters Six and Seven)

Voicing silences is stage three of the framework. Phases one to three of stage three are located in chapter six and marked the analysis of the collected data. During the analysis, the aims and objectives were revisited to reflect on whether these were being met. Stage three also enabled the exploration of the collected data or the 'voices' of the participants whose perspectives are the cornerstone to this research. Embedded within the silences framework is a phased analysis tool which Serrant-Green (2011) pointed out is cyclical as well as phased. Although the phased analysis provided a platform for a group of professionals to discuss and explore the data provided by the women participants, it provided further opportunity for the women participants to explore the findings of the professionals group. The final analysis was then performed

by the researcher. However, this stage of the silences framework was modified from Serrant-Green (2011) original phases of analysis; FGM survivor participant collective voices were relocated to phase three of the analysis.

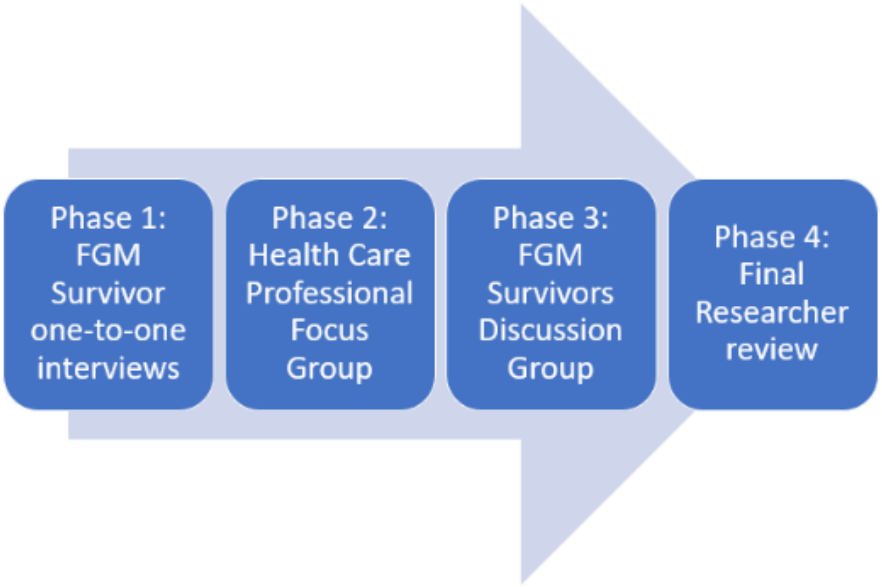

Figure 3: Stage 3 phases of analysis (adapted from Serrant-Green, 2011)

The rationale for this amendment was to ensure that FGM survivor voices were not further silenced by the health care professional group discussion. Relocating the professionals' voices to phase two of the analysis cycle provided an opportunity for FGM survivors to voice further views on health care professionals' interpretation of the initial findings as well as of FGM overall.

(i) Phase One: FGM survivor's one-to-one interviews (Chapter Six)

Phase one involved review of the data against the initial study aims and objectives to ascertain whether they were met. Within this phase, there was an acknowledgement of any relevant constraints and limitations such as existing researcher subjectivity

which may affect the validity of the findings as well as rebalancing the power relationship between the participants and the researcher. At the end of this phase, initial findings were generated for further review by the focus group of professionals.

(ii) Phase Two: Professionals' focus group (Chapter Six)

This phase of analysis was adapted from Serrant-Green (2011) concept in that collective voices were heard during phase two. This phase involved a review of the initial findings by a focus group of professionals. The aim was to ensure the assimilation of the user perspectives, address any subjectivity in researcher analysis and to ratify, refute or challenge the findings so far (Serrant-Green, 2011). This phase of analysis can encompass networks or groups or individuals who share the cultural or social communities of the participants, or any other critical friend who mirrors the social network of the sample participants (Serrant-Green, 2011). However, this study included health care professionals who are midwives and obstetric doctors involved with providing care to FGM survivors. The rationale for using this group for phase two was to reflect on the findings from phase one and identify commonalities and disparities in knowledge which may have impacted on the provision of care to FGM survivors. Discussion and reflection of this phase culminated in the second draft of findings and the silences dialogue thus far. The conclusion of the review produced draft findings for review in phase three.

(iii) Phase three: FGM survivors' focus group (Chapter Six)

Phase three of the analysis incorporated the participant interpretation and an opportunity for the women participants to consider, and respond to, the findings from

phase two of the analysis. Hence this stage consisted of FGM survivors taking part in a focus group discussion of the findings from phase two. The rationale for returning to the FGM survivors at this point was to attempt to mitigate against a potential power imbalance in the framework. In the unmodified version of the silences framework, the FGM survivors would not have had an opportunity to analyse and respond to the findings from phase two. Potentially, this may have led to further marginalisation whereby the health care professionals may have rationalised the findings from phase one but mitigated against any negative data by justifying practice within the parameters of guidelines, policy and statute. This may have resulted in the FGM survivors being further silenced by the health care professionals during analysis. Yet this was a significant opportunity for the researcher to hear the FGM survivors' collective responses to the views and opinions of the health care professionals' analysis of the initial findings. The conclusion of this phase of analysis informed the findings for analysis at phase four.

(iv) Silences Dialogue

The silences dialogue is an important step within the phases of analysis in that it is at this point that this may ratify, refute, challenge or contextualise the findings thus far (Serrant-Green, 2011). However, the term *silences dialogue* is an oxymoron; this leads to question how dialogue can be created from silence. Therefore it was more suitable to term this section as emerging concepts or silences. But, Serrant-Green (2011) explained that the 'silences dialogue' is usually generated in phase two which potentially ratifies or challenges the findings following the collective voices. However for this study, phase four was a more suitable position for the silences dialogue since the findings from all participant groups are further analysed in discourses. Furthermore,

Serrant-Green (2011) supports the modification of the analysis in this way by stating that the methods and strategies within the research depend on the placement of the silences dialogue. As such, the essence of the silences dialogue has been subsumed into phase four.

(v) Phase Four: researcher review (Chapter Seven)

The final phase of analysis concluded with a final researcher review and reflection of the previous phases of analysis. The interpreted findings represent the themes from the perspective of the women participants, ratified by professionals' and survivors' perspectives. At this point, the discourse within the interpreted themes was analysed in conjunction with the literature to identify power, vulnerability and agency within the literature as well as the themes that emerged from the data. Furthermore, Serrant-Green (2011) pointed out that the methods of analysis are driven by the needs to address the aims and objectives. Since one of the aims of this study is to consider the language used when providing maternity care to FGM survivors, such analysis was considered appropriate once phases one to three of analysis were complete.

2.4.4. Silences stage four: Working in Silences (Chapter Eight)

Stage four of the framework provides a platform for the presentation of the findings of the research and the discussion and recommendations for further research. This also includes discussion of how the research aim and objectives were met and if new silences have emerged as a result of the research. In addition to the discussion of findings, there is further discussion of any other risks or limitations that may arise as a result of the study. The risks and limitations are located in the conclusion; chapter nine.

This stage facilitates a critical reflection on the contribution of the research to the literature, practice and policy and considers how the researcher and collective voices have impacted on the research as well as how (or whether) the research had impacted on the participants. It also seeks to develop recommendations across a number of relevant and/or appropriate domains, including informing clinical practice.

2.4.5. Silences stage Five: Planning for Silences (Chapter Nine)

Serrant-Green (2011) describes stage five as a platform within the silences framework for recommendations regarding service delivery action planning. Serrant-Green (2011) identifies this stage of the framework as planning for silences. This research was conducted for the purpose of adding new knowledge which will impact on education and/or care delivery to improve the maternity experience for FGM survivors. Hence this stage of the framework provided an ideal opportunity to inform recommendations for policy and education changes as well as recommendations for service provision within the sphere of maternity care and potentially wider health care.

2.5. Chapter summary

This chapter has presented the ontological and epistemological perspectives of this study. The ontological perspective is situated in the critical and feminist theories within the post-modernist paradigm. This study is also epistemologically challenging due to the potential of multiple realities emerging. Furthermore, the researcher position within the research is also challenging; whilst the researcher was an outsider to the FGM survivor participants, they were an insider to the health care professional participants. Therefore, there was significant risk of a power imbalance in the relationship with the

FGM survivor participants and the researcher. As a result, reflexivity became crucial throughout the research and thesis completion.

This chapter has also presented the sound of silence framework which was used to structure the research. Whilst the silences framework has not been used as a theory in this study, it has provided structure to the research and aligned to the theories inherent to this study. The following chapter presents a historical background to FGM with an attempt to provide cultural understanding and rationale for the practice.

CHAPTER THREE: UNDERSTANDING THE RATIONALE OF FGM

3.0 Introduction

FGM is reported to have existed in some form for several millennia (Macfarlane and Dorkenoo, 2014), with various reasons given for the practice. This chapter explores the history of FGM as well as considering some religious connotations which suggest some justifications for the practice which may help to understand the interpretation of the practice in western society. Furthermore, this chapter will also consider FGM from a cultural context; this includes a comparison to cultural practices in western society to FGM as well as human rights in relation to the practice. The chapter concludes with a reflection of FGM on health which may impact on health during childbearing.

3.1. Historical and religious context

The debate of FGM and the attribution to a religious connotation is often controversial; since there has been no specific mention or requirement of the practice identified within religious texts, the debate is often fraught with condemnation. Moreover, the practice of FGM is known to pre-date contemporary religious orders such as Christianity and Islam, yet it is known to be practiced amongst communities within these religious groups (Abraham, 2010). Hence in order to gain further insight into the practice and how the religious affiliation may have been born, a journey to the conception and beyond of contemporary religions is crucial in an attempt to uncover the practice and its defining meanings.

3.1.1. Ancient Egypt

The earliest available documented evidence of circumcision is with reference to an Egyptian Lector Priest, Uha, around the 7th to the 10th Egyptian Dynasty (2250 - 2134 BCE). A Lector Priest was employed to recite spells and hymns in the temples during official temple ceremonies (Accetta et al., 2014), and the position of Lector Priest was considered to be a noble one. Figure 4 is an image of the funerary stela of Uha that was initially considered to include a reference to FGM. A funerary stela was a small stone tablet that was placed within the sarcophagus of the deceased person. It is suggested that Ancient Egyptian "funerary stelae" were created as a pre–cursor to modern gravestones; on an individual's death, funerary stelae were created in order to preserve the name of the person (Lloyd, 2014).

An early translation of the inscription of the funerary stela of Uha included a reference to the circumcision of 120 males and 120 females (Dunham, 1937). However, Egyptologists have since argued that the stela only mentioned male circumcision and that the translation included female circumcision due to the notion that the practice was allegedly widespread in ancient Egypt. Yet, despite anecdotal attributions of FGM to the ancient Egyptian society, there is no recorded or documented evidence that FGM occurred during this time; unlike male circumcision that was depicted on an ancient Egyptian relief of Necropolis at Saqqara as illustrated in Figure 5. Still, regardless of whether FGM was documented during the ancient Egyptian era, there was no other reference to a religious connotation. Therefore, it is important to attempt to identify when the religious connotation occurred.

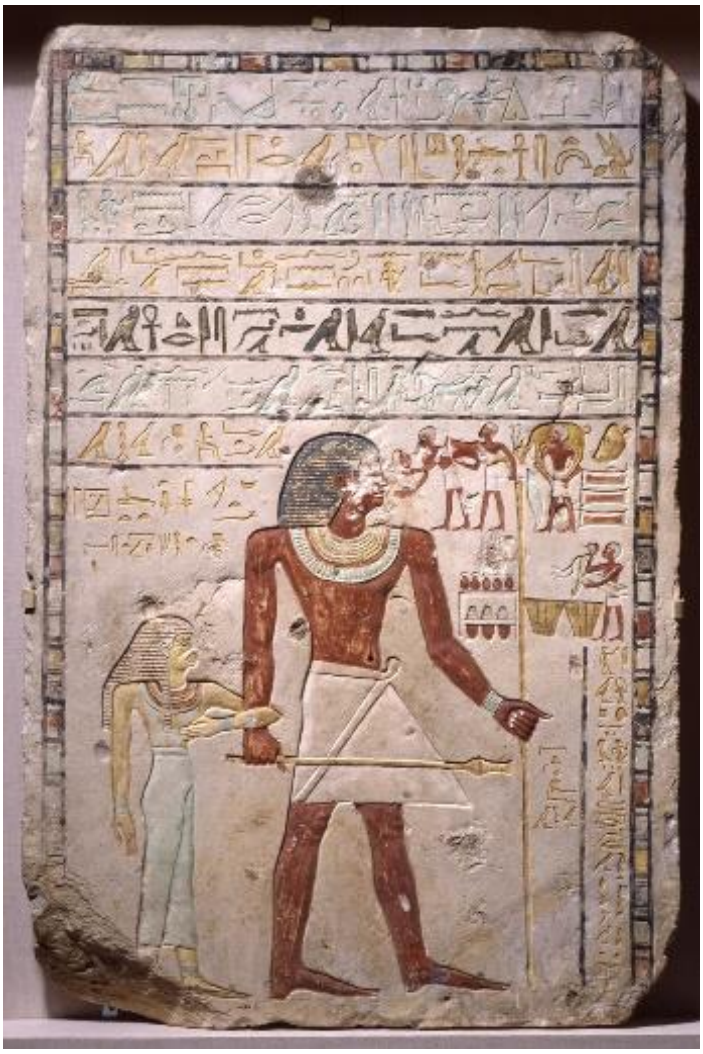

Figure 4: Funerary Stela of Uha (Vayera, 2014)

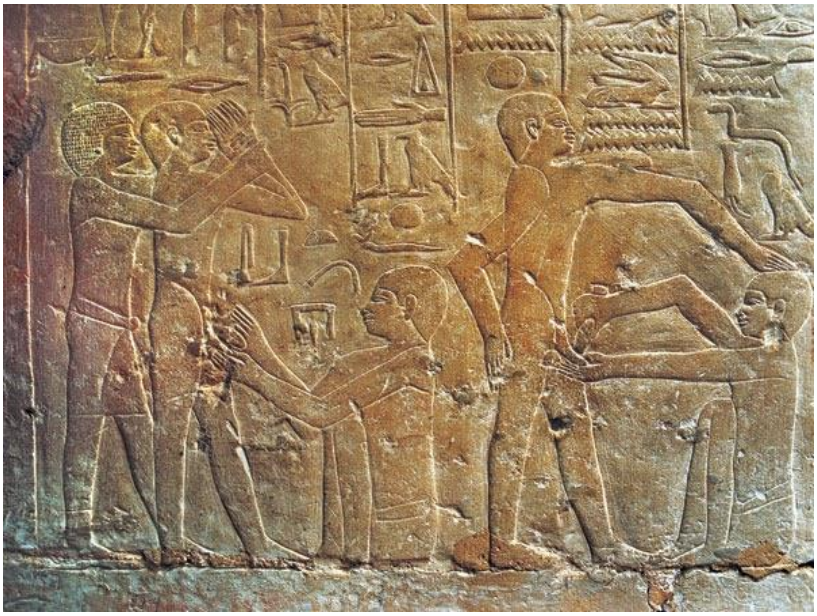

Figure 5: Relief of Necropolis at Saqqara (Vayera, 2014)

3.1.2. The Old Testament

The act of circumcision and ritual cleanliness is discussed in the books of Genesis and Leviticus (Unknown, 2012) It is an element of the Torah; described as the Written Law. The Torah is written into the five books of Moses, known as the Pentateuch, which is a component of the Old Testament (Brown, 2014). Whilst there is no specific mention of FGM in these texts, there are traditional stories that relate to alteration of the female genitalia in relation to these.

3.1.3. The Book of Genesis

In Genesis chapter 17, it is stated that Abram made a *b'rit* or covenant with God which culminated in the establishment of the Jewish people and thus converted his name to Abraham. A component of the covenant was *b'rit Milah* or rite of circumcision; literally translated as the covenant of the cut (Abusharaf, 2006). This was a token of the covenant where the male members of society sacrificed the penis prepuce to strengthen the covenant and reinforce it as an everlasting status;

> *(10) This is my covenant with you and your descendants after you, the covenant you are to keep: Every male among you shall be circumcised. (11) You are to undergo circumcision, and it will be the sign of the covenant between me and you. (12) For the generations to come every male among you who is eight days old must be circumcised, including those born in your household or bought with money from a foreigner […] (14) Any uncircumcised male, who has not been circumcised in the flesh, will be cut off from his people; he has broken my covenant."*
>
> *Genesis Ch 17: v10-14*
>
> *(King James Version)*

An uncircumcised male is said to have broken the covenant that Abraham made with God and, as a result, cast from his community (Unknown, 2012). As such, circumcision became a societal norm; yet there is no mention or mandate of FGM in this chapter of Genesis. Despite the lack of a direct reference in Genesis, Abu-Sahlieh (1995) highlights a connection between the traditional story of Abram and FGM; depicted by the alleged circumcision of Hagar by Sarai.

3.1.4. Sarai and Hagar

Sarai, who became known as Sarah following the covenant made between God and Abraham, was identified in Genesis as Abram's spouse. Genesis, verses 16–21 said Sarai was unable to conceive a child. She allegedly instructed Abram to take her Egyptian servant, Hagar, in order that she could bear a child for Abram. The union of Abram and Hagar resulted in the birth of Abram's son, Ishmael. Genesis chapter 16:6 stated that Sarai treated Hagar harshly following her union with Abram and thus Hagar fled.

However, a version of this story includes reference to FGM; one that was not depicted in Genesis. The story continued that Sarai became jealous of Hagar following her conceiving a child, and according to Shiite and Sunnite traditional stories, Sarai swore to mutilate Hagar (al-Hakam and Torrey, 1922). The stories suggest that Abram agreed Sarai could circumcise Hagar in order that it would become a tradition amongst women. But the lack of irrefutable, documented and physical evidence of FGM from that period casts doubt on this story. Equally, the origin of Abram himself was questioned since it was suggested that Abram was in fact a Pharaoh or king due to the suggestion in Genesis of his wealth and his descendants being kings (Lyons, 1997). It is further documented in Genesis that Hagar was an Egyptian slave girl. There is some anecdotal evidence which suggests during that period Egyptian slave girls were ritually circumcised to prevent pregnancy, but also that FGM was heralded as a practice reserved for the wives of the Pharaohs (Mackie, 1996). There are traditional stories that the wives of Pharaohs would infibulate their genitalia in order to prove their fidelity and devotion to the Pharaoh whilst they were away fighting wars; however, such stories are anecdotal. However, these stories may add credence to the justification for FGM and the overwhelming condemnation of these traditional stories may act to silence those who have placed cultural value in them. Furthermore, one of the colloquial terms in contemporary society that is used to describe type III FGM is Pharaonic circumcision or ‘Pharaon’ or ‘Phroni’ (Ariyo et al., 2015); this may suggest an association with Pharaohs and elevated status. The association of elevated status with FGM suggests a contradiction to the assumption that women who have experienced FGM are victims, abused and tortured. Nevertheless, this ambiguity renders it impossible to ascertain whether the practice existed at that time, the motivation for the practice or whether a customary, ritual practice became religiously

affiliated by coincidence. Still, there are further suggestions of biblical texts where the requirement of FGM may have been interpreted.

3.1.5. The Book of Leviticus

In Leviticus chapter 12: 1–5 it was written of God's request to Moses regarding the ritual cleansing of women following childbirth:

> *(1)The Lord said to Moses: (2)Say to the Israelites: If a woman conceives a child and gives birth to a son, she will be unclean for seven days—just as she is during her menstrual period. (3)On the eighth day, the flesh of the boy's foreskin must be circumcised. (4)For thirty-three days the mother will be in a state of blood purification. She must not touch anything holy or enter the sacred area until her time of purification is completed. (5)But if the woman gives birth to a daughter, she will be unclean for two weeks—just as she is during her menstrual period—and will be in a state of blood purification for sixty-six days*
>
> *Leviticus Ch12 v1-5*
>
> *(King James Version)*

There was a differentiation between the births of males and females with respect to the length of this cleansing; on the birth of a male, the woman's period of uncleanliness was to last seven days whereas on the birth of a female, this uncleanliness lasted for 14 days. The birth of a female child may suggest a belief of female uncleanliness; the woman's ritual cleansing may have been doubled to account for the female offspring. The b'rit Milah was therefore allegedly adopted by women following childbirth as an act of ritual purification and cleanliness (Abusharaf, 2006); the token sacrifice became the clitoris prepuce (Margani, 2002).

However, there was no evidence to substantiate that women adopted the practice as a method of ritual cleansing and any form of FGM has historically been forbidden under Jewish Law (El-Damanhoury, 2013). Yet, the Falashas, a Jewish minority group who have lived in Ethiopia since approximately the 8th century BCE, ritually practice FGM. But Birkner (2010) argued that this practice does not indicate a religious rationale, it is merely a coincidental occurrence since the Falashas reside in the geographical location where prevalence is high. Nyangweso (2014) concurs with this notion and argued that the Falashas Jewish affiliation was questionable due to their inherent differences from conventional Jewish practices. Furthermore, many of the Ethiopian Jews eventually migrated to Israel and abandoned the practice on settlement. Despite the lack of evidence to support the Falashas religious affiliation to the practice of FGM, Cohen (2005) pointed out that only a Jewish woman was permitted to perform the ritual circumcision. Besides there is further evidence that suggests other minority religious groups performed FGM; Coptic Christians for instance.

3.1.6. Christian Copts

Coptic Christianity was based on the teachings of St Mark and was formed around the first Century AD when a sector of Christians migrated to Egypt during the reign of the Roman Emperor Nero (Casper, 2012). Coptic Christians migrated through Egypt during the first century AD and by the mid-second century were found in parts of Upper Egypt. Coptic Christianity occupied a central role in Christian theology and devoutly defended the Christian faith (Shatzmiller, 2005). Nineteen centuries later, Coptic Christianity exists in contemporary society in Egypt, as well as in the global community; 13-15% of Egyptian people and 10-60 million people globally affiliate with the Coptic

Church (Zavada, 2013). So, it is important to identify whether there is a link between Coptic Christianity and FGM or whether this is due to geographical location.

A Coptic Bishop, Youssef (2014), stated that FGM conflicts with the divine ideologies and acts to disfigure 'God's creation'. However, in earlier literature, Abusharaf (2006) argued that Sudanese and Egyptian Copts have practiced both male circumcision and FGM with the rationale given in the book of Genesis; namely the inception of the practice of circumcision as practiced by Abraham. Although, it can be argued that the rationale of the minority of Coptic Christian's practicing FGM is also due to geographical location of the inception of the Copt rather than religious affiliation or rationale. Furthermore, there are other Christian sects who support the practice of FGM. Dorkenoo (1992) suggested that the Russian Skoptozy, a Christian Sect, believe that the Gospel of Matthew, Chapter 19:12 illustrates the Bible's support of FGM, and have interpreted this as such;

> *"For there are some eunuchs which were born from their mother's womb, and there are some eunuchs which were made eunuchs of men; and there are eunuchs which have made themselves eunuchs for the Kingdom of Heaven's sake. He that is able to receive it, let him receive it."*
>
> *Matthew Ch19:12*
>
> *(King James Version)*

The use of the term 'eunuch' has been historically used to refer to men who have undergone castration and were usually employed in the bed chambers in harems (Wilson and Roehrborn, 1999). On analysis of this chapter in Matthew, it suggested that self-castration may have been performed for religious purposes. Yet, there was no reference to either Abraham, circumcision or FGM.

So, although FGM has not been mentioned or indicated by this religious text, the Russian Skoptozy society may have either interpreted this chapter as a mandate for FGM or manipulated the meanings of the chapter to enforce FGM. Whichever the motivation, the practice can be interpreted from religious texts according to each society's interpretation of the texts rather than actually defining the practice within the religious text itself. Furthermore, other communities within religious groups continue to extract rationale from religion as a means of practicing FGM.

3.1.7. Islam

A number of Muslim communities continue to draw rationale for the practice from religion; yet it is also crucial to note that the practice is not specifically identified as authentic in any of the religious texts; including the Islamic holy texts. The Islamic faith is derived from the monotheistic teachings of the Prophet Mohammed which encompasses the Qur'an, sacred Sunnah and Hadith. The Qur'an, the holy book of the Islamic faith, was revealed to the Prophet Mohammed in stages and intended to correct any inaccuracies in previous religious texts such as the Old and New Testaments (Shafti, 2013). In conjunction with the Qur'an, Muslim people also use two further collective texts for reference; sacred Sunnah and Hadith. Sunnah is said to depict the examples and practices of the Prophet's life and Hadith clarifies what the Prophet said or approved of (Shafti, 2013). Abusharaf (2006) pointed out that in one of the hadiths of the Prophet Mohammed's female companion, Umn Atiya, "*Akhfidhi wa La tanhiki*" was stated which in a literal sense has been translated as "do not cut deep, cut at the surface of it." Although this hadith has never been authenticated, it has given validation to the practice of FGM by a number of Muslim communities. Nonetheless, Islamic scholars condemn the practice.

In an earlier paper, Ṣabbāġ (1998) argued that the hadith of Umn Atiya, who is reported to have performed and coveted FGM, is a poor hadith that has never been authenticated. Robinson (1998) concurred and maintained that FGM is a social custom rather than a religious requirement. In parallel, it can be argued that the geographical locations of the practicing communities are the crucial factor rather than interpretation of text. So, it can be further argued that the religious affiliation is a subjective interpretation of a cultural practice rather than a mandated religious requirement.

Yet with reference to unheard voices around religion, it can be argued that the interpretation of religion or religious meanings may have the effect of silencing individuals or groups due to lack of knowledge or understanding of a particular religion. On the other hand, Reiss's (2002) theory of religious affiliation can provide some insight into religious rationale of FGM regardless of the religion. Reiss (2002) pointed out that groups who affiliated more with a specific religion exhibited a desire for honour in association with religion and the need to demonstrate loyalty to parents, ethnic groups and heritage. This also aligns with culture and Nishida's (1999) cultural schema theory.

3.2 Culture

From an anthropological perspective, culture consists of learned behaviours and patterns of behaviour; a very powerful and manipulative tool in any society which is easily made changed and lost (O'Neil, 2006). Culture also consists of values; elements of common shared concepts and beliefs about what is right and wrong (Franchi, 2014). These values, when received a cultural value, are integrated into cultural heritage.

Ultimately, any given society is composed of varying elements of cultural heritage. Furthermore, culture is equally a complex phenomenon and the difficulty in quantifying the relationship between culture and language has long since served as an enigma to linguists (Nall and Nall, 2009). In addition, culture is not necessarily fixed, but can adapt temporally and spatially in the same way that language and terminology can shift.

Cultural terms used for FGM describe the practice as female circumcision and an element of a rite of passage ceremony into adulthood rather than a singular *procedure.* For some communities, intrinsic to this approach is the philosophy of purity or maintaining purity. Yet, this is contrary to the opinions expressed in the Hosken Report which describe FGM as violence against women (Hosken, 1979). The Hastings Report took a difference stance and highlighted that the global coverage of FGM infers one opinion that has been embedded into western society since the publication of the Hosken Report (Abdulcadir et al., 2012). Still, an explanation of the practice of labiaplasty is yet to be considered which is growing as a culture in western society.

3.2.1. Comparing cultural practices: FGM and Labiaplasty

A growing cultural practice in western society is genital cosmetic surgery. RCOG (2015) stated that cosmetic surgery to the female genitalia, known as labiaplasty, vaginoplasty or hymenoplasty, is permitted for purposes of self-esteem, body image, comfort, mental and psychological health and sexual confidence. Yet it can be argued that the practice of FGM in communities who support the practice can result in the same effects as described by the RCOG. It can therefore become problematic when a

female from a community who practices FGM presents to a western society gynaecologist requesting genital alteration with a psychological rationale.

In parallel, it is equally problematic to distinguish whether the individual has been coerced into presenting to gynaecology services with the remit of genital alteration; particularly since reasons given for a rationale of female genital cosmetic surgery may not be physically obvious. Nonetheless, in 2013, the RCOG raised the age for this type of genital surgery to 18 years in an attempt to alleviate this issue (RCM, RCN, RCOG, Equality Now, 2013). Yet, it can be argued that there are many communities that perform FGM in early adulthood or prior to marriage, which renders this safeguard as ineffective. However, it is further noted that when deciphering the terminology of the Female Genital Mutilation Act (2003), this constitutes alteration to the genital organs for non-medical reasons; a form of FGM as defined by the WHO. Abdulcadir et al. (2012) concur with this notion and stated that labiaplasty in western society is merely an adoption of the practice of FGM. Abdulcadir et al. (2012) further pointed out a lack of equality in the rationale of labiaplasty; women in western society are offered ethical and legal protection of genital alteration due to the procedure being controlled by western society medicine, but women who are alien to western society are deemed as deviant for carrying out similar acts.

This debate continues to draw condemnation from both sides and remains a contentious issue. It can be argued that western society will never facilitate an end to the practice of FGM whilst labiaplasty continues to be an approved procedure in western society. In parallel, the argument surrounding the popularity of labiaplasty and

condemnation of FGM may facilitate the widening of discourse and unheard voices amongst FGM survivors. Notwithstanding the differing methods used to perform each procedure, it is necessary to identify how the practice has become embedded into two very different cultures for what appears to be similar goals. However, ethno-linguistics application of cultural schemas can afford insight into the construction of these cultural practices.

3.2.2. Cultural Schema

Schemas (or schemata) are interpretations and organisation of information in the world around us. Nishida (1999) defined the cultural schema as familiarity and knowledge of a situation within an individual's culture. Nishida presented cultural schema theory as a group of past experiences that have been cognitively organised within a specific societal group. A simplified illustration of Nishida's explanation of the formation of cultural schemas can be seen in Figure 6.

The cultural schema theory can be pertinent to societies where FGM is an intrinsic cultural element of a particular society. Although it has not been possible to identify the root of FGM, the practice has been integrated into societies from generation to generation as a cultural heritage of that society. For instance, some communities incorporate FGM into a symbolic ritual marking the transition from childhood to womanhood.

The cultural explanation coincides with the practices of the Bondo Society in Sierra Leone. Bosire (2013) described the Bondo Society as being dedicated to continuing

the rituals of FGM which is reinforced by the politicians within Sierra Leone due to the secret society of the Bondo ordering and maintaining communities in the country. The Bondo Society initiates girls; prepares them for womanhood, marriage and motherhood. The Bondo teach respect, healing with the use of herbal medicine, teach cultural and traditional songs, dances and cooking methods. An element of the initiation is morality and sex education; part of which is the practice of FGM.

The initiation is shrouded in secrecy and women who have been initiated into the Bondo, described as the sisterhood, wear white headscarves as a symbol of their transition (Anon, 2005). This signifies a cultural identification and acts as a powerful societal cohesive.

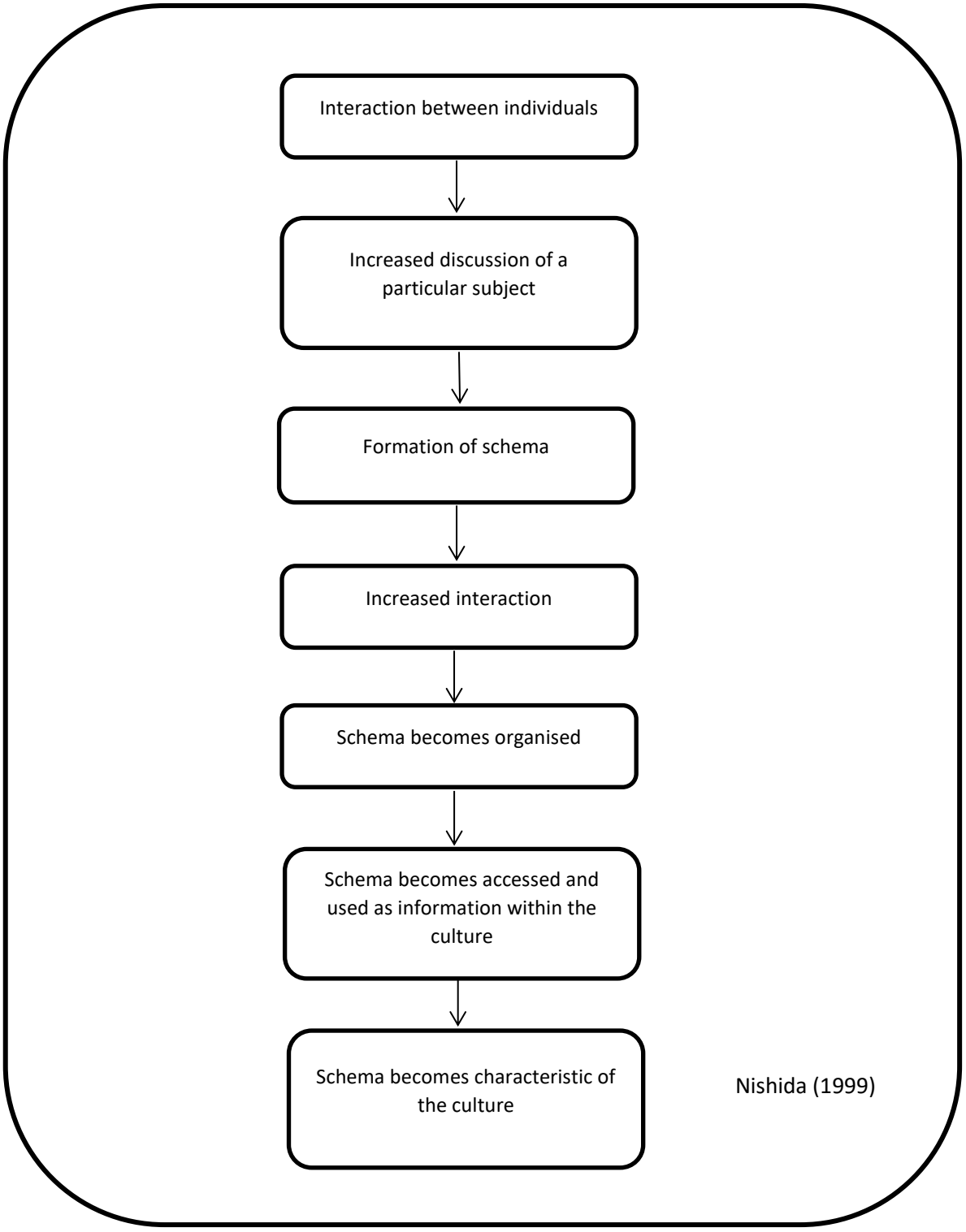

Figure 6: Simplified illustration of Cultural Schema Theory (Nishida, 1999)

3.2.3. Comparing the cultural schema of FGM and Labiaplasty

The culture surrounding labiaplasty is dissimilar to the Bondo Society rationale yet can be interpreted using Nishida's theory. Labiaplasty is performed for reasons of self-consciousness, comfort and arguably, vanity. Although difficult to ascertain a conclusive origin of this, it is suggested that increasing media images of 'bodily perfection' may contribute to the aspect of genital vanity. Hence, these media images may be a root of this cultural shift into valuing the 'perfect female genitalia'.

Nevertheless, contemporary western society argues that the rituals surrounding FGM are performed forcibly on girls from infancy to puberty and beyond. The RCM and the RCN condemn the practice and concur with the philosophy that FGM is child abuse and recognise all women and children who have experienced FGM as victims of crime (RCM, RCN, RCOG, Equality Now, 2013). Equally, all female children who are born into families within England and Wales who have experience of FGM are identified as 'at risk'. As a result, RCM, RCN, RCOG, Equality Now (2013), issued Intercollegiate recommendations with regard to identification and reporting of women and girls in the UK who have undergone FGM. The report recommended treating FGM as child abuse and making appropriate referrals to safeguarding children's boards, collating and documenting information on FGM; including the associated complications, sharing information with multi agencies such as health, social care, education and the police. Yet it can be argued that the emphasis on victimhood from the perspective of RCM, RCN, RCOG, Equality Now (2013) may contribute to the cross-cultural disparity in discourse which may lead to FGM survivor voices being unheard or not listened to.

In contrast, there has been an example where children have performed FGM upon themselves in a belief that they did not belong to their society with their genitalia intact. Thomas (2003) described this in the Ngaitana controversy following the 1956 cliteroidectomy ban in Meru, Kenya. The term *Ngaitana*, roughly translated to 'I will circumcise myself' was attributed to a group of pre-pubescent girls. These girls, who were ridiculed for their self-FGM, formed groups with the remit of recruiting peers in order to circumcise each other in defiance of the ban. It was reported that the girls stole razor blades from a local store and the group cut each other's genitalia in order to conform to older girls within their social group. In order to modify any damage that the girls had done, cutters[14] were often called upon to complete the FGM process (Thomas, 2003). Gust (2014) described this as an anti-colonial act and a re-assertion of the importance of the identity of the society and discontinuing the practice would result in irreparable damage to the culture.

Arowolo (2010) described colonialism on the African continent as an attempt to purge African culture due to the perception of its primitive, archaic and unacceptable practices. Arowolo (2010) further stated that there is differentiation between culture and civilisation in that culture is a way of life in people's shared philosophy, attitude and creativity. Whereas civilisation, particularly western civilisation, is suggested to be a specific superior lifestyle and way of life that seeks to eradicate many unacceptable phenomena such as harming others. Kasongo (2010) concurs with this notion and points out that the act of colonialism and enforcement of western civilisation in African countries was to mask the material interests that western countries had in African

[14] The term 'cutter' is used to refer to an individual who is paid to perform FGM

resources. As a result, many of the traditional African cultures, religions and languages were purged during the colonial period. This period ended as late as the mid-twentieth century with attempts at decolonisation. However, one practice that was not purged was FGM. Njambi (2004) further describes the anti-FGM movement as a construct of colonialism and describes anti-FGM campaigns as labelling Africa as a 'land of torture' whilst the west as the lands of 'freedom and liberty'. The AWA-FC take this stance in that FGM is a cultural practice that has endured the colonial period and is an important element of African heritage (Ahmadu, 2009).

FGM is deeply enshrined in cultural heritage as an act of purity by some of the societies that practice it. However western society's expectation of universal conformation to philosophies and ideals is based upon one interpretative perspective that appears to ignore cross societal and cross-cultural differences. As a consequence, there remains little understanding in western society of the rationale underpinning the practice of FGM and seems to perpetuate the notion of victimhood. With perceived passivity and negativity projected onto the women who have experienced FGM, the subject of FGM continues to be sensitive and taboo. Women are referred to safeguarding, and potentially social care and the police, due to the perception that their children are at risk of FGM and the assumption that all members of communities where FGM is prevalent support the practice. This may result in fear, increased marginalisation and perpetuation of silence amongst the communities of FGM survivors due to a threat of police and social care involvement. Furthermore, this may lead to increased workload on professionals which may further result in a lack of resource for those particularly in need. As a consequence, it can be suggested that FGM survivors in the UK do not

receive adequate care due to western society's misunderstanding of the culture and perpetuating silence.

In some cultures, it is suggested that women who live in societies where FGM is practiced are cast from their communities if they renounce the practice (Anon, 2005). Burrage (2015) points out that a girl who has not experienced FGM is considered to be promiscuous and viewed as a 'westernised girl' who is disloyal to her culture. This suggests a comparison between the philosophies of male circumcision and FGM which correlates with Reiss's (2002) theory of religious affiliation. Equally, FGM is widely practiced as a means of proof of virginity. Burrage (2012) further argues that proof of virginity is strongly associated with childhood forced marriage; however, forced marriage and childhood forced marriage is outside the scope of this study. This notion is widely reflected in western society and accepted as a reason or consequence of FGM. With this association, the practice of FGM is considered to be a violation of Human Rights.

3.3 Human Rights

Human rights are defined as the rights one has simply because one is human (Equality and Human Rights Commission, 2019). In essence, human rights provide every individual, whether male or female, adult or child, with respect and dignity wherever one lives in the world. The concept of human rights was first defined by Cyrus the Great in 583 BC; they declared racial equality and each individual's inherent right to choose their religious affiliation (Dhwty, 2014). These fundamental declarations that were recorded on a clay-baked cylinder, known as the Cyrus Cylinder, became the

precursor for many human rights documents including the Magna Carter in 1215, the Petition of Rights in 1628 and the United States Constitution in 1787 (Dhwty, 2014). The Cyrus Cylinder's provisions are also noted amongst the Articles in the Universal Declaration of Human Rights (UDHR) (1948). Yet in order to appreciate the contemporary significance of Human Rights and how FGM violates human rights, it is important to understand the concept of the UDHR.

3.3.1. FGM and Human Rights

The UDHR was a concept born from Franklin D. Roosevelt's 1941 State of the Union Address. The speech, commonly known as the four freedoms speech, specifically encapsulated freedom of worship, freedom of speech, freedom from want and freedom from fear. The speech was made in response to the atrocities of World War Two; atrocities that were born, performed and perpetuated in western society during the War. The concept of the UDHR version of human rights has its roots in individualism, but those who practice FGM do not prescribe to the same values of individualism as western society. For instance, the philosophy of the UDHR appears to support an ethnic absolutism perspective; a view that all societies and communities are in agreement that rights and wrongs are universal. The overarching philosophy of the UDHR is that all humans should have equal rights regardless of their status in any given community or society. This is particularly pertinent when considering the philosophy around freedom of speech and the unheard voice of the FGM survivor.

In societies and communities where FGM is practiced, individuals make decisions based upon the best interests of the community rather than of the individual (Almroth et al., 2001). Nevertheless, the UDHR encompasses an individual's right to health,

freedom of speech and religion, freedom of opinion and expression, freedom from slavery and the right to freely participate in the cultural life of the community (UDHR, 1948). The AWA-FC emphasise a woman's right to practice FGM in association with article 27 (1) of the UDHR which provides women with a human right to cultural and traditional practices within their given society (Ahmadu, 2009). Yet, despite the UDHR's declaration that an individual has this right, intervention by western society aimed at halting the practice of FGM has been the focus of many human rights groups for decades, which the AWA-FC oppose. This suggests ambiguity in the universality of the UDHR and a distinct cross societal and cross-cultural difference in interpretation. Furthermore, this ambiguity is augmented when considering the social and cultural practices in western society that are not only harmful but have extensive research-based evidence of the significant harm caused.

Tobacco and alcohol use are widely accepted in western society, but the global death rates that have been linked to tobacco use alone are estimated at six million per annum (WHO, 2012). Furthermore, although the legal age of consent for tobacco use in the UK was raised to 18 in 2007, and despite the recent decline in smoking (Rowell, Evans-Reeves and Gilmore, 2014), research has suggested that people begin smoking at a younger age than the statutory age (Field, Burke and Cooper, 2013). Furthermore, research suggests that people begin smoking due to peer pressure; and this pressure is cemented by the media through advertising and character portrayal in films where iconic people are seen smoking. A similar method has already been identified where societies practice FGM; the Ngaitana controversy for example as discussed in section 3.2. Even so, smokers also acknowledge that habitual smoking leads to a myriad of poor health outcomes, yet as tobacco smoking is legal, smokers are provided with

protection of the UDHR's freedom of choice. This leads to question whether parents who smoke in close proximity to children should be subject to the same philosophy as parents who arrange for FGM for their daughters. This leads to further question whether parents smoking in close proximity to their children understand the health consequences of second-hand smoke that has been highlighted by research or whether they choose to believe that it will not affect their child. In comparison, it can be further queried whether parents of daughters who have passed through the rituals surrounding FGM share this philosophy. Although the health connotations for both are obvious, there are few statutory instruments to protect the health of children of smokers in private. Despite the recent introduction of the prohibition of smoking with children in cars (Patterson et al., 2015), it can be argued that this is an extremely difficult law to enforce. Nevertheless, both second-hand tobacco smoking and FGM are detrimental to health, yet FGM receives public condemnation; this may be rationalised using the spiral of silence theory. Furthermore, with both second-hand smoke and FGM known to have a detrimental effect on an individual's health, a definition of health is required to understand the effect that these have on a person's health.

3.4 Health

The WHO has defined health as complete physical, mental and social wellbeing. Essentially, this definition has endured since its inception and has not been reviewed since 1948, therefore can be interpreted to suit any society. If this definition is interpreted from the perspective of a community that practices FGM then the practice can be construed to fulfil elements of this definition of health; namely, the fulfilment of psychological, spiritual and emotional wellbeing. But, it can be construed that from a western perspective the practice of FGM completely contravenes the universal

definition of health. A further cross-cultural disparity in discourse is identified where there is potential for the FGM survivor's voice to be unheard. As a result, this difference of understanding can impact on the relationship between the woman and the health care professional when an FGM survivor becomes a user of health services in western societies. Potentially, this can render the FGM survivor silent due to their voice being continually unheard as a result of ineffective cross-cultural communication. Clark et al. (2011) concur and point out that unless the patient and the healthcare professional share the same values on health and its definitions then a fundamental lack of cross-cultural understanding is perpetuated.

3.5 Chapter summary

This chapter has presented historical and religious context of FGM. Although the origin of FGM remains unknown, there is suggestion that FGM was practiced more than 4,000 years ago. Whilst there is no direct mandate in religious texts to perform FGM, some societies may have interpreted meanings in such texts as a mandate for FGM.

This chapter has also explored culture in relation to FGM and has compared some cultural practices in western society with FGM. Cultural schema has been discussed in relation to FGM in an attempt to understand the cultural construction of FGM as well as in comparison to the western culture. Human rights have been considered in relation to FGM and how human rights could be open to interpretation. This chapter has concluded with a discussion of FGM and its effect on health.

The following chapter marks the commencement of the stages of the silences framework with the critical review of literature relevant to this study.

CHAPTER FOUR: WORKING IN SILENCES (STAGE ONE)

4.0 Introduction

The purpose of this chapter is to critically review the available and relevant literature which relates to the maternity experiences of FGM survivors and the knowledge of health care professionals who provide care in maternity services. In doing so, this contextualises the perspectives of care from the FGM survivors and health care professionals.

This stage is orientated to critically examining current, existing knowledge of FGM that is relevant to this study. Furthermore, presenting the views of insiders and outsiders of the practice aims to provide insight into the discourse between the FGM survivor and health care professional in maternity services. In addition, discursive objects in language and terminology are analysed to ascertain whether cross-cultural interpretation has an impact on discourse between FGM survivors and health care professionals. Guidelines and health care professional education are examined in detail due to the intricate links with these and health care provision and legislation is considered and whether the insider views are incorporated into statute or whether the statute itself affects cross-cultural discourse. This chapter will conclude with the main themes related to the research focus and how these themes justify the need for the study.

4.1. Literature search

Prior to the concept of this study, a significant amount of literature on FGM had been collected by the researcher. However, these were mainly journal articles and editorials

from clinicians providing care to FGM survivors and their families. There was very little good-quality research available on FGM from the perspective of FGM survivors and their families; where studies were available, these were conducted using health care professional participants. Whilst there was no formal search strategy at that point, internet searches were carried out on databases such as Google Scholar, CINAHL and MEDLINE on a two-monthly basis to determine whether new publications arose. These searches took place between February 2006 and January 2011 and originally commenced due to completing an undergraduate module on sexual and reproductive health with FGM being used as the subject. Nevertheless, at the time of collecting this data, there was little understanding of the relevance of recording search strategies and the hits on databases. As such, a reflexive point for the search strategy is to ensure all literature searches and database hits are recorded.

4.1.1. Search Strategy

The experience of FGM survivors was central to my interest in this study which formed the basis of my literature search for this study. Hence the search strategy consisted of a search of literature using the terms 'female genital mutilation', 'FGM', 'female circumcision', 'FGM/C', 'genital cutting', 'genital mutilation', 'cliteroidectomy', 'infibulation' and 'traditional African initiation ceremonies'. Furthermore, the experience of FGM survivors' experience of maternity services was the focus of this study so the search also included the above terms in conjunction with 'pregnancy', 'maternity', 'midwifery', 'antenatal', 'childbirth', 'labour', 'perinatal', 'postnatal' and 'obstetric'. The search extended to CINAHL, EMBASE, MEDLINE, the Cochrane library, Google Scholar, Hansard text, books describing first-hand accounts of experiencing FGM, religious texts, newspaper articles from western society as well as from countries

where FGM remains prevalent; the search strategy can be found at Appendix XV. Furthermore, the search included a search of 'grey literature' such as clinical policies, guidelines as well as social care and safeguarding policies. This was achieved by searching guideline and policy databases on websites such as the RCOG, the RCM, the RCN as well as the Department of Health and NHS England. The use of grey literature in this study was particularly useful in understanding the rationale for the provision of care and where gaps (or silences) existed in the current knowledge and provision of care to FGM survivors in the maternity setting. The initial search took place between September 2011 and January 2012; following this, an alert was established (where possible) on these databases and was reviewed during January 2015. Literature was added into a database and sorted by title and abstract and relevance to the study; a sample of which can be found at Appendix XVI. The result of the database forms the basis of this chapter which led to the strengthened justification for this study.

4.2 FGM in the UK Maternity Services

Due to global migration and asylum, FGM is now apparent and growing in many areas of western society (Cook, 2016). In view of this, there has been a growing number of FGM survivors presenting to maternity services (O'Connell, 2014; MacFarlane and Dorkenoo, 2014; Varol et al, 2016). Government guidance was published in February 2011 with the remit of providing effective care to individuals who have experienced FGM or those at risk of FGM (HMSO, 2011). Midwives are in a unique position to identify FGM survivors due to the nature of the care that they provide and risk assessments carried out in the early antenatal period. However, this relies heavily on FGM survivors disclosing their FGM status or being aware that they have an FGM status. Subsequent guidance such as the Intercollegiate guideline (RCM et al, 2013)

was aimed at the safeguarding aspect of FGM. Therefore, care provision from a culturally responsive perspective had been overlooked.

The majority of NHS Trusts do not provide specialist services for FGM survivors; there are currently 21 specialist services across England and Wales which are specifically for FGM survivors (FORWARD, 2019). Reasons given include a lack of available funding, few women historically presenting who have been affected by FGM and the belief that any service for FGM survivors can be integrated into other 'vulnerable women' services when women access the NHS for maternity services.

It has been recognised that specialist services for FGM survivors are also provided under the vulnerable women umbrella; the research site is an example of this. Yet, it has been suggested by Creighton et al, (2016) that due to the complex and individual needs of the affected women, a stand-alone service is required to meet the complexity of needs for this group of women. However Brownjohn (2018) argued that all front-line health care professionals should be trained to provide tailored care to meet the needs of women living with FGM which would alleviate the problems of services concentrated in specific areas and sporadic service provision in other areas. With adequate training, all midwives could be in a position to identify populations or individuals that have experienced FGM in the community, provide support and education and refer women to appropriate agencies when required.

Momoh (2001) pointed out that the midwife's role in identification of FGM survivors is an expanding role; the inclusion of FGM training should be core curricula of the

midwifery training. But their role should expand to cultural awareness as well as an understanding of mental health triggers. Cameron and Rawlings–Anderson (2001) concur and highlighted the need for health professionals to be adequately educated with regard to clinical and cultural implications. Daley (2004) further pointed out the adverse obstetric outcomes for FGM survivors such as increased risk of haemorrhage, keloid scarring that renders vaginal birth impossible (Figure 7) and obstructed labour due to insufficient opening of the vaginal orifice (Figure 8). Daley (2004) further stated the need for midwives to have an understanding of FGM and the context of practice. Yet, none of this evidence includes hearing the voices of FGM survivors; these statements pertain to clinicians. Furthermore, Cameron and Rawlings–Anderson, Momoh and Daley do not give any further indication of the lack of education at student level or recognising and hearing the voices of FGM survivors.

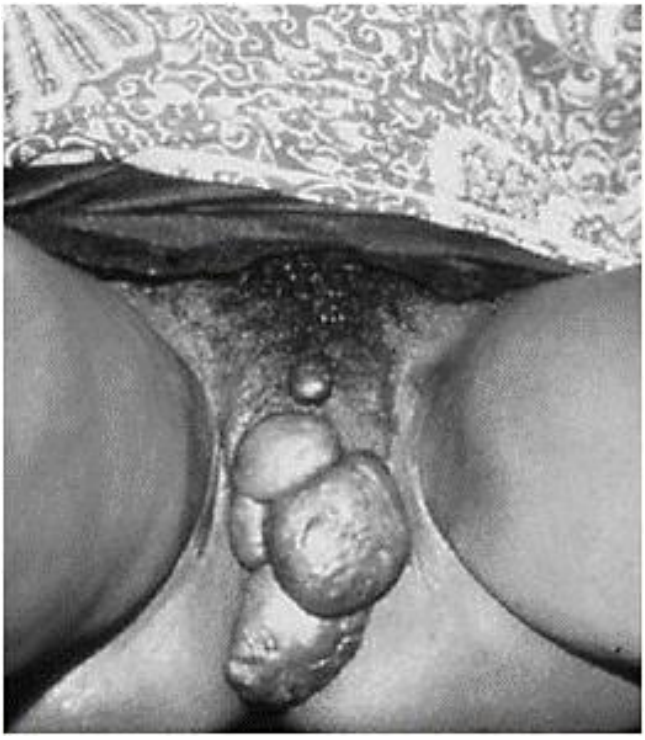

Figure 7: Keloid scarring as a result of FGM (RAINBO Organisation, 1994)

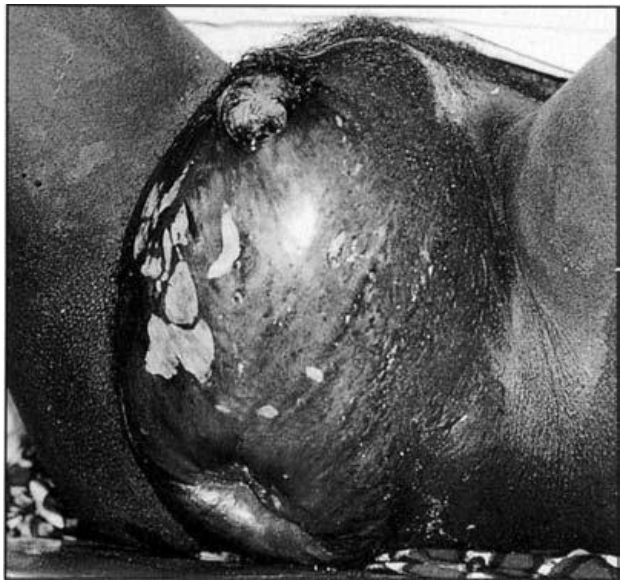

Figure 8: Obstructed labour due to FGM type 3 (RAINBO Organisation, 1994)

Sihwa and Baron (2004) highlight the need for midwives to be educated to a level to ensure comprehensive support for women, but less than 10% of delegates at a university conference in 2004 were aware of legislation to safeguard women and children against FGM; despite this being introduced a year earlier. This was compounded by statistical evidence showing that 81.8% of maternity units in England and Wales did not historically offer awareness training to midwives in areas of low prevalence such as rural areas; 38% felt that due to low prevalence rates of FGM, training was not required (Lavender et al, 2006). It appeared that areas where prevalence was low had not historically provided training on identification of women and girls who have experienced FGM. However, since the Girl Summit, there has been a shift towards education in safeguarding which has in turn impacted on the education in the health care sector; all professionals from health, social care, education and law enforcement are required to undertake awareness training on FGM (DH, 2014). Nevertheless, education which is freely available is produced by, and in association

with, the Home Office and is heavily threaded with legal aspects and implications of FGM. As a result, this may lead to fear amongst FGM survivors and result in silence amongst this community as well as voices being unheard.

Furthermore Dorkenoo et al (2007) noted that, statistically, FGM is increasing within the UK as a whole; international migration of women from FGM practising countries is growing. The current estimation in the UK of childbearing women who have experienced FGM is 137,000 with suggestions that this figure is likely to increase due to mass migration into Europe from African and Asian nations (Macfarlane and Dorkenoo, 2014). Furthermore, although widespread, large-scale prevalence of FGM is confined in England and Wales to densely populated inner-city areas such as London, Birmingham and Liverpool, but FGM survivors can reside in any area of the UK. Dorkenoo (2007) concurred and further pointed out that small pockets of women who have experienced FGM now reside in suburban and rural areas that have historically low or no FGM survivor communities. Following the initial national data gathering period in 2014, there were 72 areas in England that reported no women identified with FGM. But, the FGM dataset for quarter four of 2017 had identified 22/72 (31%) of those areas where women who have experienced FGM have not historically resided in but now have small prevalence rates (NHS Digital, 2017). This has been highlighted in more recent media reports which have indicated that areas which did not have any historical or contemporary reports of FGM prevalence are now reporting cases of FGM[15][16]

[15] Hook, J and Linham, L. (2018) The scale of female genital mutilation in Somerset revealed. Somerset Live. This media report indicates that patients have been treated in the Somerset Hospitals who have experienced FGM where historically prevalence is zero.

[16] The Royal United Hospitals in Bath had recorded 10 cases of FGM to NHS Digital (2017). Historically, FGM prevalence in Bath is zero.

Furthermore, one of the recommendations from Dorkenoo (2007) study is the incorporation of FGM education into the core curricula of students of health, social care, education and police. However, there has been no succeeding research-based evidence regarding the needs of healthcare students' requirements of FGM training or whether training has been successfully embedded in these sectors. It can be argued that without adequate, culturally sensitive training, student midwives, and indeed midwives, will not recognise all forms of FGM, therefore many of these women remain unreported.

Each of these studies highlights that midwives have an integral role in the identification of FGM and the delivery of care tailored to women who have undergone FGM. Moreover, it is recurrently suggested that midwives require specific training in order to competently deliver this care; however there has not been any study to specifically illustrate the level of training that exists or the success of identification with student midwives as part of the core midwifery programmes or the specific training requirements for student midwives, as well as midwives and obstetricians, with respect to FGM. Furthermore, education around FGM requires an understanding of communication with FGM survivors and how ineffective communication can lead to FGM survivor voices being unheard or not listened to; this includes understanding the terminology and language used which relates to FGM.

4.3. Language and Terminology used for FGM

Analysing opinions and experiences is central to this study; therefore language and terminology play a key role throughout this research. When addressing the terminology of a subject it is crucial to understand the meaning of terminology in order to appreciate

why a specific term is used to describe a subject in question and what consequences result in the use of a specific term. Yet terminology is spatial (Brown, 2004); the same entity can vary from one society to another and from one culture to another dependent upon the belief, the environment or importance of the subject in each society or culture.

Equally, terminology is temporal (Dyke, 2003); evolving and adapting to integrate into contemporary society and also back in time. An example of this in western society is the term *gay*. Until the mid-twentieth century, the term was generally used to refer to enjoyment or experiencing pleasure. However, the term evolved during the latter part of the twentieth century and is now used in reference to homosexuality (Bedell, 2007). Furthermore, due to historic negativity directed at homosexuality, the term gay is often used in a negative context (Bedell, 2007). Yet, terminology used for FGM can be complex due to interpretation and translation of cultural terms.

It is problematic to understand all of the terms used to describe FGM since some terms are expressed in languages that do not have written values (Anderson, 2012). In these cases, it is impossible to quantify a divergence between the cultural term and a western society interpretation. However, one can attempt to identify an equivalent translation for a number of cultural terms used for FGM.

Table 2:4 illustrates a number of terms used in various societies and cultures to describe FGM. Note that some of the terminology and the rationales highlighted in the table are very different from those used in western societies. For instance, one of the terms used to describe FGM has connotations of purity. Essentially, purity is defined

as being undiluted or unmixed with extraneous material, untouched or undefiled and encompasses a woman's virtue or chastity (Hawker, 2006).

Table 2:4 Terminology used to describe FGM (Abusharaf, 2006)

Country	Term	Rationale
Egypt (regional)	Thara (from the Arabic Tahor)	Purity
	Khitan	Circumcision
Eritrea	Mekhnishab	Circumcision
Ethiopia	Megrez	Circumcision
	Absum	Name giving ritual
Gambia	Niaka (to clean)	Purity
	Kuyango	"the affair"
	Musolulu Karoola	"Women's concern"
Guinea Bissau	Fana du di Mindjer	Circumcision
Kenya	Kutairi	Circumcision
Mali	Bolokoli	Circumcision
Nigeria	Ibi or Ugwu	Circumcision
	Sunna	Religious or tradition
Sierra Leone	Bondo	Initiation rite into adulthood
	Sunna	Religious or traditional
Somalia	Halalayas (from the Arabic Halal which implies purity)	Purity
	Gudiniin/ Qodiin	Circumcision/ Infibulation
Sudan	Tahoor (also derived from Tahor)	Purity
	Khifad	Lowering the height

In order to attain this virtue or chastity until marriage, the process of FGM is performed. Yet the nature of FGM itself is alteration of the genitalia so does not conform to the

definition of purity. However, the element of the definition that describes a woman's virtue suggests that this is the part of the definition that encompasses FGM. Furthermore, the word *mutilation* is polarised from purity which may explain some individual and community renouncement of the term FGM.

(i) Impact of the term FGM

Chapter one outlined the use of the term FGM regarding the description of the act itself. But at this point, the terms used to describe FGM are analysed, how these impact on FGM survivors and whether silences manifest in the actual terms used to describe FGM. The description 'female genital mutilation' and the acronym 'FGM' was conceived by Hosken (1979) following the Hosken Report and adopted by the WHO in 1991 as the universal term used to describe the practice. Yet, Hosken's situatedness to the research within the Hosken Report needs to be understood and how the term may have been conceptualised.

Kahn (2006)[17] described Hosken as a white, wealthy middle-class woman who was engaged in American post-war social activism for women. This became embedded in the second-wave feminist movement which Hills-Collins (1998) described as main-stream and opposed black feminist views. Furthermore Thompson (2016) argues that second-wave feminism was white-led, marginalised black women and used sexism as the ultimate oppression of women. Roth (2003) went further and argued that while black feminism and white feminism emerged simultaneously during the second-wave

[17] Kahn, J. (2006) wrote the obituary for Hosken in the Boston Globe newspaper (12th February 2006) following her death on 2nd February 2006.

feminist movement, some white feminists were personally racist; as a result, black feminism became marginalised. However Cichocka et al. (2013) pointed out that one of the aims of second-wave white feminism was to strive for gender equality regardless of race. Yet in relation to FGM, Lane and Rubinstein (1996) argued that this led to an impasse between the universalism of white feminism and cultural relativism of black feminism; with white feminism largely disregarding historical and cultural issues.

Lane and Rubinstein (1996) went further and stated that Hosken's label of 'mutilation' suggested intolerance of the communities who they had intended to help. Lane and Rubinstein (1996) refer to FGM as *female genital surgeries* and *female circumcision* due to the term *mutilation* being a 'detached description and dehumanising'. Abdulcadir et al. (2012) concurred with this notion and argued that the term female genital mutilation and the acronym FGM serve to marginalise and denigrate women who have passed through initiation rites into adulthood where FGM has been part of the initiation. As a result of this, it can be argued that the term FGM has served to marginalise FGM survivors. Yet, Assaad (1999) previously pointed out that the term genital surgery is an unhelpful term due to the term *surgery* being a respected medical term which may subsequently add respectability to the practice.

While the impasse regarding terminology appears to be an issue of ethnocentrism, there are FGM survivors who also have opposing views to the term. For instance Dirie and Wardere, who are both FGM survivors, ratify the use of the term FGM due to the physical and psychological trauma that they experienced. However, Ahmadu refutes the term FGM due to the stigmatisation and vilification of a cultural practice.

4.4. Legislation

Since 1985 there have been provisions in the UK to protect women and girls against the practice of FGM. In England the Female Circumcision Act 1985, which was superseded by the Female Genital Mutilation (FGM) Act 2003, provided protection for women and girls at risk of, and who had undergone, FGM. The fundamental aspects of the FGM Act state that an offence of FGM is committed when;

> - *Excision, infibulation or mutilation of any part, or all, of a girl's labia majora, labia minora or clitoris is performed,*
> - *Encouraging or assisting a girl to excise, infibulate or mutilate any part of her labia majora, labia minora or clitoris,*
> - *Assists, encourages or procures a non-UK national or permanent UK resident to perform any of the acts identified above on a girl outside of the UK*
>
> *(HM Government, 2003).*

However, exceptions to this include procedures performed for mental or psychological health as well as procedures performed during childbirth (HM Government, 2003). Despite the Act being extended to include protection for individuals who were declared permanent residents within the UK, the Act did not protect individuals who were resident in the UK who were claiming asylum. Equally there is some confusion in the Act around practices that encompass Type four FGM, which includes genital piercing. Whilst this is a growing cultural practice in western society, it also falls into the category of FGM. Therefore, it appears that this type of FGM was not illegalised in legislation.

In addition, the Act stated that an offence was not committed where a procedure was carried out for the physical and mental health protection of girls. However, it may be extremely difficult to ascertain that girls are not being coerced into FGM for psychological or mental health purposes and ultimately renders the element of

coercion in the Act as futile. Furthermore, it is notable that although the statistical estimates of women and girls within the UK who have undergone, or who are at risk of, FGM have continually risen; only one prosecution has been made since the inception of the FGM Act.

Moreover, in the 2014 Bar Human Rights Committee (BHRC) report of FGM in the UK identified the gaps in the Female Genital Mutilation Act (2003) and declared that the UK had failed in its duty of care to protect women and girls of FGM and identified 12 recommendations (Appendix IV) to protect these groups. Amongst these recommendations, the BHRC recommended that UK law ensured FGM became a mandatory education requirement for all professionals who provide care to women and girls who have experienced FGM (Dias, 2014). These statutory instruments were embedded in the Serious Crimes Act 2015.

The Serious Crimes Act 2015 attempted to alleviate a number of the discrepancies of the FGM Act by including women and children who were not permanent residents of the UK. The Serious Crimes Act further introduced female genital mutilation protections orders (FGMPO). Under this provision, passports can be seized to prevent girls from being taken abroad with the intention of FGM being carried out (HM Government, 2015).

Nevertheless, despite the practice being banned in the UK, FGM is intrinsic to some communities and social groups, and there does not appear to have been an abatement of the prevalence of FGM, despite the silence surrounding the practice. Indeed, it is

noted that the number of women and girls in the UK who have been identified with FGM has continued to increase. It is therefore imperative that education remains a key factor in identifying women and girls who have experienced FGM as well as continued evolution of knowledge provided by the health, social care and education sectors to women and girls.

4.5. Guidelines, recommendations and health impacts of FGM

Policies and guidelines on FGM and health impacts of FGM are inextricably linked; particularly in relation to maternity care. However, there are other policies which are focused on the safeguarding aspect of FGM so will also be examined in this section. It has been claimed in the majority of literature that FGM has a considerable impact on a woman's health; these claims are discussed in this section. Furthermore, the WHO (2018) stated that the consequences of FGM are sub-divided into short, medium- and long-term consequences which appear dependent on the situation and/or environment. The RCOG (2015) provided guidance and recommendations to health care professionals working in UK maternity and gynaecology care; therefore, due to this study exploring FGM survivors' experiences of UK maternity care, this guideline is examined in detail.

In 2009, RCOG published their first national guideline on the management of FGM in survivors; this was superseded by an updated version which was published in 2015. RCOG (2015) indicated that the guideline is a provision of evidence-based guidance on clinical care with due regard to the health implications of FGM. The guideline further includes health care professionals' legal and regulatory responsibilities.

The guideline is presented in four discrete sections: (i) legal and regulatory responsibilities of health care professionals, (ii) complications related to FGM, (iii) clinical assessment and care planning and, (iv) clinical practice; the majority of clinical care is focused on obstetric care. The first and most prominent recommendations within the guideline are the legal and regulatory responsibilities which suggests that RCOG deem these of utmost importance. Although there is little to no evidence for the legal and regulatory recommendations, these are requirements for all health care professionals which are mandated and embedded in statute by the UK government (HM Government, 2003; HM Government, 2015).

With regard to complications related to FGM, RCOG (2015) sub-divided complications into short and long-term complications. Short-term complications are listed as: (i) haemorrhage, (ii) urinary retention and (iii) genital swelling. The evidence for these complications was referenced to a systematic review and meta-analysis of FGM on physical health by Berg et al. (2014). Although RCOG (2015) acknowledged that the methodological quality of the studies was poor, the evidence level was classified as 2+ level of evidence[18]. Nevertheless, RCOG (2015) listed these recommendations as 'good practice'[19]. On review of Berg et al. (2014) it was noted that the evidence was very poor. For instance, although RCOG (2015) stated that haemorrhage was an immediate complication (5-62%), the studies used for Berg et al. (2014) systematic review reported no haemorrhage in 90% of cases. Therefore, this suggests that RCOG (2015) may have mis-classified the evidence that underpinned this recommendation.

[18] 2+ classification of evidence states that the evidence is well-constructed case-control or cohort studies with a low risk of confounding, bias or chance and a moderate probability that the relationship is causal.
[19] Good practice points are graded as recommendations based on the clinical experience of the guideline development group, with no evidence from clinical-based research.

Further evidence within RCOG (2015) regarding long-term complications of FGM was analysed. However, there was little evidence other than expert opinion and case studies. For instance, RCOG (2015) stated that urinary tract symptoms are more common in FGM survivors, however Berg et al. (2014) argued that the quality of research in this area was poor. Amin et al. (2013) identified that survivors of types II and III FGM had a higher risk of lower urinary tract symptoms than women with no FGM. In parallel, Iavazzo et al. (2013) conducted a systematic review of FGM and infections in an attempt to uncover clinical evidence of this and identified that urinary tract infections (UTI) was common in FGM survivors. Nevertheless, Iavazzo et al. (2013) concluded that there was no indication in any of the studies regarding the clinical testing and diagnoses of infection in FGM survivors or how the results were obtained. Furthermore, Ferry et al. (2009), who conducted a randomised placebo controlled study of urinary tract infections in women, pointed out that the association between symptoms of UTI and bacteriuria was unpredictable and required rapid diagnostic testing to confirm the diagnosis of UTI. Despite there being no indication whether FGM survivors were included in Ferry et al. (2009) sample, it suggests that the evidence of FGM and increased UTI in RCOG (2015) is questionable.

Maternity and obstetric care is a dominant feature in RCOG (2015). Although experimental, NHS Digital (2018) data suggests that 85% of FGM survivors who access health care are reported by maternity services. Therefore, it is important that clear, evidence-based guidance is available for these health care professionals so that care is optimal during this time. However, RCOG (2015) pointed out that there is little

evidence surrounding obstetric complications in FGM survivors due to poor methodological approaches and has applied 2- as the level of evidence[20].

RCOG (2015) posited that women in the UK from FGM practising countries may be at a higher risk of stillbirth and neonatal death. However, on examination of the evidence used for RCOG's guideline, this has been classified as 2-. Gissler et al. (2009) pointed out that although stillbirth and mortality is higher amongst migrant communities, there is no evidence suggesting a causal link with FGM. Furthermore, Small et al. (2008) found that women born in Somalia were more likely to give birth to babies in poor condition. However, there is no explanation in Small et al. (2008) regarding reasons for this and suggests that due to 97-99% of Somali-born women living with type III FGM the association with FGM and stillbirth may be an assumption.

The clinical recommendations in RCOG (2015) encompasses clinical assessment to determine the type of FGM as well as planning care tailored to meet the FGM survivor's needs. RCOG (2015) further indicated that individuals such as midwives, obstetricians and gynaecologists should remain competent in all aspects of FGM, including safeguarding standards; with a midwife and obstetrician lead responsible for the care of FGM survivors. RCOG (2015) stated that FGM requires a multi-agency response and education remains key. The education and knowledge of health care professionals on FGM are discussed in section 4.6. Safeguarding is a key theme within national FGM guidance therefore a detailed examination of such guidance is required to understand the motive for this involvement.

[20] RCOG evidence level 2- encompasses case-control or cohort studies with a high risk of confounding, bias or chance and a significant risk that the relationship is not causal (RCOG, 2015, p25)

HM Government published multi-agency guidance in February 2011 with the remit of providing effective care to individuals who have experienced, or those at risk of, FGM (HM Government, 2011). The guideline is significantly threaded with reference to FGM survivors as victims. For instance, section 4.7 of the guideline refers to a 'victim-centred approach'. Although this may potentially be true of child FGM survivors, referring to women as victims rather than survivors infers a negative connotation which may impede their transition to survivor status. Section 2.10.2 of the guideline indicates long-term health implications of FGM; many of which are outlined in RCOG (2015). HM Government (2011) referred to an increased risk of HIV and other sexually transmitted infections, however Iavazzo et al. (2013) pointed out that HIV is prevalent in regions where FGM is practised and there is a greater likelihood of contracting HIV due to coital bleeding rather than the FGM procedure itself.

RCM, RCN, RCOG, Equality Now (2013) intercollegiate recommendations aimed to improve identification and reporting of women and girls in the UK who have undergone FGM. The guideline recommended treating FGM as child abuse and making appropriate referrals to safeguarding children's boards as well as collating and documenting information on FGM; this includes the associated complications and sharing information with other agencies such as health, social care, education and the police. The emphasis on victimhood from the perspective of RCM, RCN, RCOG, Equality Now (2013) was closely aligned with HM Government (2011) and may have further contributed to the cross-cultural disparity in discourse which may lead to FGM survivor voices being unheard or not listened to.

4.6. Health Care Education

Examining the education on FGM that is currently provided to health care professionals was an important consideration for this study. The care provided to FGM survivors is dependent on the knowledge and awareness of health care professionals; the foundation of which is derived from health care education. Currently, there are two packages of education that can be freely accessed by health care professionals; one is provided by the Home Office and the other is provided by Health Education England. Both of these education packages are widely available to any health care professional; these include nurses, midwives and doctors of any discipline and students of these professions. Furthermore, the Home Office training package is available to a wider audience which includes social care, the education sector and police forces.

Health Education England, in collaboration with key stakeholders, developed the e-learning for health programme to provide online training for health care professionals on the subject of FGM (Reisel et al., 2016). The package encompassed topics such as (i) communication skills, (ii) legal and safeguarding issues, (iii) management of FGM with children and young women, (iv) management with women during pregnancy and (v) psychological impact. However, it was noted that all those who contributed to the training package were living, and educated, in western society (UK) and therefore provided an outside opinion only of the practice. Whilst there were specific case studies embedded within the learning programme, few of these were based on the FGM survivor voice. Furthermore, in the introduction chapter, an overview of FGM describes type IV as:

> *"all other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterising the genital area"*
>
> (Reisel et al., 2016)

This reflects the terminology used in the FGM Act (HM Government, 2003). As such, this implies that the many women in western society who choose genital piercing for decorative purposes are interpreted as self-harming as a result of their genital piercing.

There was particular emphasis on the victim agency with language used such as 'suffered' and 'affected'. For instance, chapter two provides information for clinicians regarding communication with FGM survivors during clinical consultations. The introduction of this chapter includes:

> *"Consulting with patients who have suffered FGM […] you should also be non-judgemental – FGM can provoke strong feelings […] clinical communication that you are likely to need when dealing with a patient affected by FGM."*
>
> (Reisel et al., 2016)

When examining the language used for this introductory page, there are several issues. Whilst there is reference to including the patient in the consultation by using the words *consulting with patients*, the patients are then deemed to have suffered FGM which suggests a victim philosophy. Clinicians are then urged to be *non-judgemental* due to potential provocation of *strong feelings*. However, there is no explanation of what these strong feelings might be or whether the strength of the feelings may be positive or negative. Furthermore, whilst there may have been an attempt to balance

the power between the FGM survivor and health care professional at the beginning of this excerpt due to consultation *with the patient*, power is removed from the FGM survivor with the final sentence of this excerpt with use of the words *dealing with a patient* and *affected by FGM*.

A further example is statement three on values and beliefs. In this section, there are a series of statements and answers which can be agreed with, disagreed with or not known. Statement three pertains to a health care professional's reaction to FGM:

> *"When I learn about the practice and procedures that are involved with FGM, I feel sickened and outraged. The practice distresses and horrifies me and I feel powerless to do anything about it. Do you agree or disagree with this statement?"*
>
> (Reisel et al., 2016)

However, regardless of the response provided to this statement, the feedback given to this question includes:

> *"These feelings are appropriate as we learn more about the procedures and practices of FGM, and the suffering it causes […] it is also important that we don't show distress and feelings of disgust in our conversations with communities, families and individuals affected by FGM […] Who can you talk with about your feelings?"*
>
> (Reisel et al., 2016)

This feedback suggests that there is an assumption that health care professionals will feel shocked and disgusted by FGM. The word *disgust* is an extremely powerful and negative word to use when describing feelings towards a survivor of FGM. However, it further suggests that their reaction to FGM should not be shown to patients, families and communities. Yet it can be argued that conveying disgust about patients to other professionals breaches their respective code of conduct.

In a systematic review of preventable harm in healthcare, Nabhan et al. (2012) argued that improving communication can be integral to preventing harm. But using powerful words (as outlined above) in the training package may embed these feelings or values in health care professionals. Furthermore, a section on psychological impact of FGM within the learning package posited that FGM is the root of psychological issues in FGM survivors. However, this does not consider the FGM survivor voices or consider whether the health care and/or psychological intervention may manifest or conceive psychological harm.

The health care awareness predominately focuses on the identification of FGM survivors who are over the age of 18 and with the recommendation to refer to appropriate agencies. However, there was little information regarding the agencies that health care professionals should refer women to. Furthermore, the pregnancy section of the learning package pointed out that women were more likely to test positive for HIV and other blood borne viruses due to the nature in which FGM is carried out (Reisel et al., 2016). Yet, as previously discussed, Iavazzo et al. (2013) pointed out that there was a greater risk of women contracting HIV from coital bleeding

than of the FGM procedure. Furthermore, the learning package recommended that deinfibulation[21] should take place around the twentieth week of pregnancy. However, there is no current evidence to substantiate this despite being identified in the RCOG guideline. Healy (2014) described this as bio-medical discourse which differentiates between who is knowledgeable (or expert) on a particular issue and who is not. Yet bio-medical discourse also profoundly influences service delivery in health care. It appears that power was constructed in bio-medical discourse; particularly in RCOG (2015) who recommended deinfibulation based on expert opinion. This power was compounded in the education package where deinfibulation is recommended at 20 weeks gestation (Reisel et al., 2016) despite a lack of evidence to support this recommendation.

The law section within the learning package appeared to align with the perspectives in the Hosken Report (which is discussed in detail in section 4.7.1). There appeared to be a totalitarian view on safeguarding whereby the FGM survivors' opinions of FGM was not taken into account and safeguarding referral should be made based on the judgment of the health care professional. This suggests a power imbalance where the health care professionals hold the power regarding safeguarding realities.

The learning package also used negative words when describing the rationales used for FGM. For instance, one statement pointed out that 'FGM is not demanded by religion' (Reisel et al., 2016) but Abdi (2007) uncovered that some communities have

[21] Deinfibulation is the surgical reopening of type III FGM

a strong belief in a religious rationale. This suggests that the beliefs of some FGM survivors are disregarded.

While the Health Education England training package is aimed at health care professionals, the Home Office training package is aimed at a multi-agency audience (HM Government, 2016). Despite this training package being developed later than the Health Education England package, there are similar notions throughout. For instance, there is a strong victim agency depicted with the word ‘victim’ being used on several occasions during audio excerpts. Furthermore, there is a parallel with the Health Education England training package in that there is a lack of survivor voice inherent to the training. Furthermore, negative ‘power’ words are used; for instance, there is a statement which points out that professionals should ‘not fear being branded racist or discriminatory’. However there is no evidence that racism or discrimination has occurred as a result of providing care to FGM survivors and their families.

The evidence in guidance and education related to health impacts and consequences of FGM has shown a lack of reliability. Furthermore, they appear to represent an outsider opinion of FGM, particularly in RCOG (2015) where multiple recommendations are based on expert opinion of obstetrics which is equally parallel to RCM, RCN, RCOG, Equality Now (2013). Therefore, outsider opinions need to be examined in comparison to insider opinions on FGM to uncover whether there is disparity in cross-cultural understanding of FGM.

4.7. Views and opinions of FGM

Two of the objectives of this study are to explore the maternity care experiences of FGM survivors as well as the experience of providing care from health care professionals' perspective. Furthermore, this study is situated in cross-cultural and marginalised discourses and whether silences exist within this discourse. Therefore, this section focuses on, and analyses, the existing views of FGM from both outsiders and insiders of the culture and practice. For the purpose of this study, outsiders are those who have not experienced FGM and do not originate from the communities or countries where FGM is practiced, whilst insiders are FGM survivors and/or people who originate from the communities or countries where FGM is practiced.

4.7.1. Outsider views

Views on FGM from outsiders of the practice have been presented in literature for several decades. Some of these views have formed the foundation of knowledge and understanding of FGM in western society. As such, analysing outsider views is an important step in understanding the root of knowledge of FGM in western society which may reflect contemporary understanding and provide a lens on the provision of education and guidance to health care professionals in maternity services.

(i) Historical Context

To provide context to the contemporary outsider view, it was important to uncover whether, from a historical perspective, any type of FGM was practiced within western society. Following the literature search, it was revealed that alteration of female genitalia was commonplace in England during the nineteenth century. The remit of this practice was 'curing' promiscuity, mental health problems and illnesses that were

described as ‘diseases of women’. Isaac Baker-Brown, an obstetric surgeon of the London Surgical home, published case studies in 1886 of the cures that were attained by surgical removal of the clitoris (Baker-Brown, 1886). However, the practice was not known as circumcision or any form of genital mutilation at this time; this procedure was referred to as ‘cliteroidectomy’. Baker-Brown attributed the clitoris as being the catalyst for many mental, physical and emotional disorders.

> *‘I was led to the conclusion that the cases which had puzzled me and defied my most carefully-conceived efforts at relief, depended on peripheral excitation of the pudic nerve. I at once subjected this deduction to a surgical test, by removing the cause of excitement… Daily experience convinces me that all unprejudiced men must adopt, more or less, the practice which I have thus carried out’*
>
> Baker-Brown (1886, p vi)

The underlying notion of each case study suggests Baker-Brown hypothesised masturbation as the root of all illnesses. Amongst the case studies within this publication was reference to curing infertility by removal of the clitoris as well as averting suicides by virtue of cliteroidectomy. Baker-Brown (1886) provided a dichotomy of prognosis which was deemed relatable to a progressive loss of nerve power in these patients due to clitoral stimulation:

> *“(i) Hysteria (including dyspepsia and menstrual irregularities)*
>
> *(ii) Spinal irritation with reflex action on uterus, ovaries &c., giving rise to uterine displacements, amaurosis, hemiplegia, paraplegia, &c.*
>
> *(iii) Epileptoid fits, or hysterical epilepsy*
>
> *(iv) Cataleptic fits*
>
> *(v) Epileptic fits*
>
> *(vi) Idiotcy*

(vii) Mania

(viii) Death

(Baker-Brown 1886, p7)

Yet, on publication of these case studies, the medical profession voted to remove Baker–Brown from the medical profession in 1887 due to agreeing that cliteroidectomy was an unnecessary and demeaning practice with no evidence of the illnesses described within the case studies. However, Sheehan (1981) argued that Baker-Brown was removed and ostracised due to claiming credit and status for a practice that other surgeons were quietly employed to carry out and as such impinged on their income. But there was another case of genital alteration in western society around this time.

Démétrius Zambaco, a French educated doctor from Constantinople, published a case study of two pre–pubescent girls who were reported to be excessively masturbating and suggested mental health problems (Zambaco, 1882). However, on closer examination of the case of the two girls, there is a suggestion that the girls were subjected to a history of sexual abuse. For example, the National Society for the Prevention of Cruelty to Children (NSPCC, 2017) identified this behaviour as an indicator that a child is repeatedly subjected to sexual abuse. Zambaco's treatment of their masturbation was to repeatedly cauterise their clitoris and labia but included branding of their buttocks in order to ensure compliance (Zambaco, 1882). Nevertheless, following this case there was no further literary evidence found that supported any afflicted injury to the female genitalia and alteration of the female genitals was deemed, in western society, to be a form of subjugation of women.

Cliteroidectomy then seemed to either disappear from western society culture or was potentially silenced.

It is noted that each of these early publications are patriarchal and sexist in nature due to: (i) the studies concluded that genitalia of the women, and the girls, was directly linked to physical and mental illness, (ii) mental illnesses in women were directly linked to clitoral stimulation, (iii) fertility was the sole responsibility of women and infertility was linked to stimulation of the clitoris and (iv) a belief that in the majority of cases, leaving the clitoris *in-situ* would result in the woman's death.

(ii) Interpretation in second-wave feminism

A prominent outsider opinion presented FGM as a practice that is physically, psychologically and emotionally damaging to girls and women who experience it. In 1979 Fran P. Hosken, a social activist and anthropologist, published observational studies of the practice of the traditional female circumcisions and ritual practices in a report, "The Genital and Sexual Mutilation of Women"; known as the Hosken Report. The Hosken Report became the singular document of reference to western society regarding the practice of FGM.

Yet, on closer examination of the report, it offers but one opinion of FGM; trauma, mutilation, violation and a subjugation and oppression of women. The Hosken Report portrays a subjective, and often demeaning, opinion of the people who practiced FGM (Hay, 2012) which, in contemporary research, gives very little value to the critical appraisal of the research and the practice. For instance, in an initial chapter on

personal views, Hosken suggested that men should undergo castration in retaliation of FGM which, according to Hosken (1979) would eliminate rape and child illegitimacy. Hosken further posited that all men were ultimately responsible for the practice;

> *'They [the procedures] represent a deliberate means to enslave women and a systematic attempt by men to subjugate women absolutely and life-long to physically control women's bodies, reproduction and sexuality. I am deeply ashamed for all men because they are ultimately responsible.'*
>
> *(Hosken, 1979, p9)*

Hosken based the content of the report on first-hand observations of the practice and interpreted these with ethnocentric and white feminist values. Yet with the historical context of western society's practice of cliteroidectomy, it may have been the only term of reference that Hosken could use to rationalise the practice that was witnessed.

The Hosken Report was presented to the WHO in 1979 at the Organisation Seminar in Khartoum where Hosken continued to campaign for the term 'Female Genital Mutilation' and the acronym 'FGM' to be used to describe the practice; it was suggested that this was the only term that reflected the harm caused. As a result, by 1991 the WHO had prescribed the term as the universal term to describe the practice. The WHO (2008) further rationalised the use of this term by stating that the term FGM bears a distinction from the practice of male circumcision and places an emphasis on the resulting harm of the practice of FGM that Hosken described in the report of 1979. Nevertheless, there is growing movement to refer to male circumcision as male genital mutilation (MGM); but this is outside the scope of this study. The WHO further stated

that the term reinforces the point that the practice is carried out on non-consenting children.

Since the Hosken Report, FGM appears to be viewed as an abusive and demeaning practice that acts as a suppression of women's sexual and reproductive health in the cultures that practice it. However, this was the interpretation of Hosken during their research. Nevertheless, Hosken's interpretation of FGM was rooted in the cultural value that western society placed on the practice following the publication of Baker-Brown's case studies. Therefore, the Hosken Report may have cultivated silence around FGM and the resulting unheard voices of the FGM survivors.

Furthermore, Hosken used powerful words to reinforce their argument. For instance, the term FGM itself includes the word *mutilation* which can be an immensely powerful, negative word depending on the context, situation and the individual who is referred to as being mutilated. When presenting their argument to the WHO seminar, further powerful words such as 'sexual assault' and 'attack on human freedom' were used to present the case for the universal term *female genital mutilation* to be implemented to describe the practice.

Despite opposition to the term, which was described as demeaning to women who had experienced the practice, Female Genital Mutilation and the acronym FGM became the internationally prescribed term used to describe cultural, traditional and religious practices of altering the female genitalia. Nevertheless, it can be argued that the acceptance of the term female genital mutilation and the FGM acronym is based on

one individual's outsider perception of the practice which was viewed through the lens of western society values and white feminism. Yet further views need to be considered for this study to provide contemporary outsider views.

(iii) Contemporary outsider views

Relph et al. (2013) conducted an observational study to ascertain the knowledge, attitude and training of FGM amongst health care professionals in London. Data was collected from 79 health care professionals; 78.5% of these were female. Whilst there was a focus on the health care professionals' knowledge and understanding of FGM, there was information on their attitude and views of FGM. Relph et al. (2013) identified that 10% of participants believed that medicalisation of FGM could potentially reduce complications and 13.9% believed that women had the right to ask for FGM as a competent adult while 87.3% would inform social services of a suspected case of FGM in a child. This suggests that the majority of health care professional participants in this study concur with Hosken (1979) in believing FGM to be harmful. Similar views were identified in other studies.

Leye et al. (2008) conducted a survey-based study of gynaecologists in Belgium to ascertain the attitudes of Flemish gynaecologists to FGM. Leye et al identified that 85.6% (n=286) of respondents believed that FGM is a form of violence against women and 60.8% (n=203) believed that FGM contravenes human rights. However, 2.1% of respondents believed that FGM deserved respect due to cultural and religious connotations. Cappon et al. (2015) conducted a similar study amongst Flemish midwives to ascertain views on FGM. The majority of respondents (93.6%; n=763)

believed that FGM was a form of violence against women and 75% (n=611) believed that FGM is a violation of human rights. Furthermore, and similar to Leye et al. (2008) 2.2% (n=18) believed that FGM is a respectful cultural tradition. It was noted that in both of these studies, quantitative methods were used for data collection which, according to Johnson and Onwuegbuzie (2004) may not provide sufficient depth of data regarding views and opinions. Therefore, each of these studies may have benefitted in using mixed-methods which could have provided further insight to the health care professionals' views. Nevertheless, the views in both of these studies appear to reflect the views of Hosken's (1979) which supports the victim agency and suggests that Hosken's understanding of the practice has embedded within western society culture.

Evans et al. (2019) conducted a systematic review of the factors influencing health care of FGM survivors from the perspective of health care professionals. Evans et al. (2019) identified 30 papers of varying relevance and methodological quality; those considered to be low quality did not describe methodological perspectives as well as the theoretical approach (Evans et al., 2019). Nevertheless, Evans et al. (2019) identified important themes encapsulating views and opinions of FGM amongst health care professionals. Many of these themes uncovered discourses between FGM survivors and health care professionals that may imbalance power within the relationship and lead to silences among FGM survivors, or health care professionals not adept at hearing their voice. For instance, Evans et al. (2019) found that when cultural understanding was reached, culturally appropriate care was provided; but care was compromised when cultural understanding was not attained. This concurred with Clark et al. (2011) who stated that unless the patient and the health care professional

share the same values on health and its definitions, then a fundamental lack of cross-cultural understanding is perpetuated. However, Evans et al. (2019) uncovered similar views to Hosken (1979).

Strong emotions of FGM amongst care providers was identified by Evans et al. (2019) which were described as shock, disgust, horror and that FGM was a negative cultural practice which left women with abnormal bodies that were deemed to be mutilated. It was also uncovered that nurses and midwives attempted to support FGM survivors and expressed sympathy and empathy with women being the ‘victims’ of patriarchal cultures that were violent and barbaric; there was a description of feelings of anger towards the men in those societies. Although Evans et al. (2019) described this as mixed emotions, it appears that this theme is strikingly similar to Hosken's (1979) victim agency belief and suggests a perpetuation of marginalisation of discourse and disparity in cross-cultural communication. Equally, it is noted that these sentiments are included in the Health Education England training package on FGM. Potentially, these emotions could lead to silence or not hearing the voice of the FGM survivors. Furthermore, cultural sensitivity was highlighted by Evans et al. (2019).

Braddy and Files (2007) stated that health care providers require an understanding of the culture surrounding FGM to achieve a trusting relationship with FGM survivors. Equally, in 23 studies identified by Evans et al. (2019) professional’s considered it important to have an understanding of the wider context of FGM from a culturally sensitive perspective. Although there appears to be attempts at bridging the cultural divide, the theme surrounding family acknowledgement identified cultural division

which suggests an imbalance of power within the relationship between the health care professionals and FGM survivors. For instance Evans et al. (2019) identified studies which referred to FGM survivors' decision making that was influenced by family members resulting in women, families and health care providers attempting to exert control in clinical situations (Evans et al., 2019). However Almroth et al. (2001) pointed out that societies and communities that practice FGM do not make decisions based on individual requirements or needs, but make such decisions based on the interests and needs of the community. This suggests a lack of cultural knowledge of the communities who practice FGM as well as an imbalance in the power dynamic between the health care professional and FGM survivor.

Ormrod (2019) conducted a qualitative study of the experiences of NHS care for FGM survivors. While the study is a useful starting point to ascertain FGM survivors' experiences of health care, there were only nine FGM survivor participants who took part in this study. While communication was identified as an emergent theme, with language difficulties being mentioned as an influence on the interaction between health care professionals and FGM survivors, all of the participants were fluent English speakers so this may have been an assumptive conclusion. Furthermore, a theme of 'silent suffering' was identified which appeared to relate to the FGM survivors' experiences of living with FGM rather than their experience of NHS health care. Furthermore, there were participant quotes amongst the theme of silent suffering that were related to communication and cross-cultural differences which did not appear to relate to suffering as a result of NHS experience but this section appeared to ratify the victim agency of FGM survivors. Equally, there was suggestion that FGM survivors were reluctant to criticise NHS care; this suggests a pre-conceived assumption that

NHS care was sub-standard for these participants. While the study is a useful start in considering NHS care for FGM survivors, a sample size of nine women is insufficient to draw any meaningful conclusions.

In many of these studies, there seems to be a notion that FGM is influenced by a patriarchal control over women; whereas in others there is an overarching notion that FGM is deemed to be violence against women. Potentially, these notions may lead to silences or unheard voices amongst FGM survivors. Therefore insider views of FGM may either ratify or refute these notions.

4.7.2. Insider views

Hearing the views of FGM from survivors of the practice were an important step to consider when attempting to understand whether patriarchal power and control is rooted in the practice. Odukogbe et al. (2017) pointed out that FGM is a practice controlled by women to ensure marriageability. This suggests that although men do not have direct control of FGM, there is an abstract element of patriarchy within the practice.

(i) Men's views from inside the culture

Outsider views suggest that men have an element of control around the practice of FGM; whether this is direct control or an abstract control. As such, it is important to understand whether the views of men inside the practice ratify, refute or challenge this notion since it appears to be embedded into western society understanding of FGM.

El-Mouelhy et al. (2013) conducted a qualitative study in Egypt to uncover men's perspective on FGM and sexual relationships. The study included qualitative views from women (n=94) and men (n=93) on decision making and justification of FGM. The study uncovered that men, and women, believed that leaving the clitoris intact results in women becoming 'oversexed' which could affect the virility of men. This appears to draw parallels to Hosken (1979) and Baker-Brown (1886). However, some of the men interviewed raised concerns regarding women not experiencing sexual pleasure which would affect marital happiness and lead to divorce. This contradicts the previous point regarding the 'over-sexing' of women and the arguments surrounding the patriarchal control of FGM raised by Hosken (1979) as well as the results of Baker-Brown (1886) case studies. Furthermore, there is no consensus in the study regarding the decision making process around FGM procedures which leads to difficulty in concluding whether men ultimately hold the power in such decisions. For example, some men considered FGM to be the responsibility of mothers and sometimes grandmothers; however younger men took an active part in family discussions in favour of FGM but believed that there was value in medical opinion in the decision making process (El-Mouelhy et al., 2013). This suggests that men do not hold the power in the decision making process around FGM and when power is shifted to, or adopted by, men this power is deferred to medical opinion or decision. Equally, this also suggests a power imbalance between FGM survivors and health care professionals.

Ruiz et al. (2017) conducted a further qualitative study to understand men's views on ending the practice in countries around the Sahara belt[22]. There were mixed views

[22] 25 men were included in this study. The men originated from: Mali, Senegal, Chad, Djibouti, Niger, Ghana and Morocco.

from the men regarding the practice itself but the quotes within the analysis suggest that men believe that the practice should end. However, there was discussion around those who hold power in the decisions, which according to Ruiz et al. (2017) lies with men. Yet there is no evidence to substantiate this notion within the study so it appears that this is an assumptive conclusion. The discussion refers to men's opinions in favour of eradication but accept that it is a gender issue. This further refutes the notion that FGM is a practice that is directly controlled by men as Hosken suggests.

(ii) Activism inside the culture

The AWA-FC, a community-based pressure group, also conflicts with the notion proposed by Hosken. The AWA-FC was conceived and born from a small group of women from Sierra Leone. Founded by Ahmadu (2009) the primary aim of the organisation was to provide an argument in favour of continuing the practice of FGM. Ahmadu (2009) posited a disparity in cross-cultural discourse between western society and those societies where the practice is commonplace. Ahmadu (2009) asserted that the practice is an element of ancient ritual practices that act as a powerful societal cohesive amongst communities and groups. Ahmadu, who originated from Sierra Leone, returned to the country at the age of 21 to experience FGM through initiation into Sierra Leone's Bondo Society.

Ahmadu (2009) provided an argument on the power dynamics within FGM from a different perspective. Ahmadu suggested that the dominance of patriarchal political control in western society aims to end the practice by bringing women's bodies under the control of western male politicians and religious leaders (Abdulcadir et al., 2012). This suggests that it is Ahmadu's view that western society's opinion of FGM acts to

silence women who either support FGM or who are survivors of FGM. Furthermore, it also suggests that Ahmadu believes that men hold greater power over women in western society than men in societies where FGM is practiced. The Hastings Center Report called for the change to be led by women of the societies but to give them the choice of experiencing FGM, as a consenting adult, as part of their cultural heritage (Abdulcadir et al., 2012). Nevertheless, the Bondo Society, which is supported by Ahmadu, has embedded the practice of FGM within initiation ceremonies that mark the transition from childhood to adulthood; this suggests that the initiation ceremony is performed in childhood.

(iii) Decision-making responsibility inside the culture

Bjälkander et al. (2013) conducted a mixed-methods cross-sectional study in Sierra Leone to determine the decision making process around the initiation ceremony. A total of 310 girls were sampled for this study[23]; however due to some girls exclusion from the study, 189 were ultimately included. The majority of girls experienced FGM between the ages of two and 14 (n=157; 83%); the average age of girls who underwent the FGM procedure was 7.7 years old. This suggests that FGM is performed on girls who may not have the capacity to consent and contradicts Ahmadu (2009) and Abdulcadir et al. (2012). The study uncovered that decisions were predominately made by female relatives (63.7% n=121), with less than a third (30.7% n=58) of male relatives taking the role of decision maker; 1% (n=2) of the decisions were made by the initiate. This suggests that the older female relatives predominately make the decision regarding the girls' FGM therefore to understand distribution of power

[23] 310 girls were sampled between the ages of 10-20 years old. The majority of girls were primary school age; 35% of the girls were illiterate. 189 of the girls had undergone FGM which was the final study sample. The average age at which FGM was performed was 7.7 years.

between men and the women of the Bondo Society, analysis of the power behind the Bondo Society is needed.

(iv) The Bondo Society

Bosire (2013) conducted an ethnographic study which explored the discourse between the Bondo Society and the political establishment in Sierra Leone. The participants consisted of 52 members of the Bondo Society; 22 of these participants were leaders in the Bondo Society (Soweis), two were members of parliament, eight were other politicians and the remainder were classified as citizens (Bosire, 2013). There were also 14 men interviewed who consisted of police officers, politicians, village chiefs and society leaders (Bosire, 2013). The study found that there was a symbiotic relationship between the Bondo Society and politicians due to the Bondo Society's network of members who provide the politicians with valuable votes during government elections. In return, the Bondo Society assert power over the success of politicians which Bosire (2013) described as 'king makers'. However, patriarchal power within the society is complex; whilst men hold power in chiefdoms, they rely on the Bondo to govern the chiefdom (Bosire, 2013). Furthermore, the Bondo leaders hold the power of traditional healing which the male chiefs rely on. Therefore, Bosire (2013) points out that power is symbiotic between the chiefs and Bondo leaders. This study shows that patriarchy and power within the Bondo is far more complex than a simple male control over women as posited by Hosken.

Ahmadu (2009) further stated that the initiation ceremonies empower women by retaining control of their bodies and sexuality. This suggests that the AWA-FC view FGM as a feminist act and not a practice used to control or subjugate women; a further

contradiction to the suggestion of the rationale of practising FGM that Hosken reported. However Ahmadu (2009) is refuted by Bjälkander et al. (2013) since it was uncovered that initiation ceremonies are conducted with children who have no power or control over their bodies or sexuality. The findings from the literature thus far appear to support the notion that women hold the power in FGM by subjugating girls and controlling their bodies and sexuality. As such, this appears to contest the knowledge of FGM in western society as a male-led practice.

(v) Insider views of the western culture of genital piercing

Genital cosmetic surgery was presented in chapter three and compared with FGM. However, a further growing cultural practice in western society is genital piercing (for both men and women). Kelly and Foster (2012) suggest that this enhances sexual pleasure as well as enabling an expression of individuality. WHO has defined genital piercing as type IV FGM. In a survey-based study of piercing sites Bone et al. (2008) body piercing was more common in women than men (46.2% of women aged 16-24 who had accessed the services) however only 2% of these had genital piercing.

In view of this practice growing in western society, Ahmadu (2009) argued that there are contradictions between western society practices and societies that practice FGM. However, it then becomes problematic to differentiate between those who have chosen to alter their genitalia with piercings, those who feel compelled to alter their genitalia for social acceptance (Kelly and Foster, 2012) and those who have had this enforced as a method of FGM. In addition, this may also pose a question of equality of individuality as well as race equality.

4.7.3. Summary of literature

This section has critically analysed the outsider and insider views of FGM. Whilst the nineteenth century literature may seem a little misplaced in this contemporary study of FGM, these appear to have formed the foundation of outsider views of the practice. It appears that late twentieth century views of patriarchy and power in gender discourse in relation to FGM are still prominent in contemporary research. As such, this suggests that an element of universalism is present with the dominant view of FGM in western society reflecting Hosken's interpretation; this is reflected in Figure 9 where it appears that a cultural silence has developed around FGM. The perpetuation of Hosken's views may have acted to marginalise FGM survivors in contemporary society; predominantly in maternity care where it appears that the majority of research around FGM is conducted. However, when considering the insider views, it appears that these are shaped by cultural relativism which reject the universalistic views of the outsider; particularly regarding Njambi (2004) reference to colonialism.

This chapter has examined maternity health care professionals' knowledge and education of FGM, the importance of terminology as well as the legislation pertinent to FGM. A critical review of current guidelines used in maternity services to provide care to survivors has uncovered unreliability in the evidence used for recommendations of care and a lack of survivor voice within these guidelines. Furthermore, the theme of all the guidelines appears to represent an outsider opinion of FGM. At best, this may be unhelpful when attempting to provide care which is tailored to meet the FGM survivor's needs, at worst, this may further marginalise FGM survivors.

Figure 9: The spiral of cultural silence around FGM. Adapted from Noelle-Neumann (1993)

4.8. Justification and gap in knowledge

The critical review of literature has uncovered gaps in knowledge that are relevant to the care and experiences of FGM survivors in maternity services. Equally, there is an absence in knowledge from a cultural sensitivity perspective; particularly in education and clinical guidance. Consequently, this may have an impact on the knowledge and understanding of health care professionals who provide such care. This section presents the justifications for this study by drawing evidence from the literature review to support the identified gaps in knowledge for investigation.

4.8.1. FGM survivors' perspectives

It was important to carry out this research due to the lack of available robust qualitative research from the FGM survivor perspective; particularly experiences of maternity care. The current knowledge of FGM in western society is based on twentieth century ethnocentric interpretation of the practice with little cultural knowledge or sensitivity. The twentieth century interpretation is based on second-wave western feminist views which may have been drawn from analysing nineteenth century practices. Although twentieth century views played an important role in bringing attention to FGM, it has served to marginalise FGM survivors. These opinions have endured and embedded in current literature and health care education with powerful, negative language and terminology used which may act to imbalance power between FGM survivors and health care professionals in maternity services.

Outsider views continue to heavily rely on Hosken's outdated second-wave feminist interpretation of the practice. This was evident in Leye et al. (2008) and Cappon et al. (2015) where views on FGM from health care professionals were interpreted as

violence against women and girls. Furthermore, Evans et al. (2019) uncovered a belief that FGM survivors are victims of patriarchal cultures which echoes the interpretation of the practice conveyed in health and other professionals' training. Since this was interpreted from health care professionals' perspectives, it is important to understand the perspective of care from FGM survivors rather than rely on outsider interpretation.

4.8.2. Evidence used to inform clinical guidance and education

The critical review of available literature suggested that evidence used to support the care of FGM survivors was unreliable. This was interpreted by critically evaluating the evidence that is used to justify recommendations in clinical guidance. Equally, such recommendations are constructed without the FGM survivors' perspective. For instance, RCOG (2015) recommend managing the care of FGM survivors based on evidence that was deemed unreliable in systematic reviews (Berg et al., 2014). It was noted that such evidence was founded from outsider opinions and studies. Furthermore, health care, and wider, education is based on similar outsider opinions which assume negative reactions. This was evident in Reisel et al. (2016) where *disgust* was used to describe potential feelings towards FGM survivors. There also appeared to be a strong power imbalance in education packages with FGM survivors often depicted as victims and language used which may act to disempower FGM survivors in their relationship with health care professionals. This was evident in the above example with the use of negative words but also when using phrases such as *dealing with a patient* (Reisel et al, 2016).

Throughout the guidelines and educational packages available to support the care of FGM survivors and their families, there was no information provided on the cultural aspects of FGM. As a result, health care professionals are educated, and tasked to provide care, from an outsider perspective with little or no cultural understanding of FGM which may perpetuate the victim-perpetrator philosophy. Hence it is crucial to uncover FGM survivors' experiences of maternity care to understand whether such care meets their needs or whether an improvement in clinical guidance and education is required to improve their experiences of maternity care.

4.10 Chapter summary

This chapter provided context to the study by identifying relevant themes and critically evaluating the available evidence around these themes. Furthermore, this chapter addressed the words within the literature, the researcher position in relation to the literature and the identification of the gap in knowledge pertinent to this research. Language and terminology have been examined, uncovering that powerful words are embedded in health care education which may act to disempower FGM survivors.

Outsider and insider views of FGM have been explored which has identified a cultural dissonance in outsider understanding of FGM and in turn, identified the absent survivor voice in guidelines, education and legislation. As a result, health care professionals in maternity care may perpetuate the victim-perpetrator perspective of FGM survivors with little cultural understanding. Therefore, in order to break this cycle, the FGM survivor perspective on maternity care is needed to understand their experiences and learn to support them and fulfil their maternity needs through health care education,

policy and statute. The following chapter will therefore address the methodology used for this research and the methods used for collecting this data.

CHAPTER FIVE: HEARING SILENCES (STAGE TWO)

METHODS

5.0 Introduction

Chapter two established the ontological and epistemological perspectives as well as the structure of this study. This chapter presents the methodological perspective that directed this study and how the silences framework guided the methods used to collect the data. There is also a description of the sample and how this was selected, the sampling methods and how the participants were recruited. Furthermore, the data collection methods, the coding and analysis strategy are presented and the chapter concludes with a section on mitigating against potential problems as well as actions to solve actual problems to prevent reoccurrence.

5.1 Aims and objectives

There were three main aims to this study; (i) to understand the maternity experiences of FGM survivors throughout their contact with maternity services, (ii) to explore how the knowledge and experiences of health care professionals can impact on the care that the women received and (iii) to understand how the terminology and language used by the health care professionals can affect the care experiences of FGM survivors. Hence there were three key questions of this research:

1. What is the maternity care experience of FGM survivors in a UK maternity service?
2. Does health care professional knowledge of FGM have any impact on the care that FGM survivors receive in maternity care?
3. Does language and communication affect the care that FGM survivors receive?

In order to answer these questions, key objectives were identified:

- Explore the experience of UK maternity services of FGM survivors
- Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors
- Critically examine the education and guidance widely available to health care professionals on FGM
- Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally
- Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.

5.2 Methodological perspective

The ontological and epistemological perspectives of this study were presented in sections 2.1 and 2.2 of chapter two. This section presents the argument for the methodological perspective used for this study. Although other approaches were considered for this study's methodological approach, it was concluded that these were not useful in answering the question of experiences, and consequently hearing the silences, in maternity care. Examples of these are ethnography and phenomenology.

Ethnography is rooted in anthropology and is broadly defined as the study of people in the field (or their natural setting) to understand their behaviour, mostly by observation (Howell, 2018). However Hammersley (2018) argued that ethnography is a wider interactionalist approach that can be polarised between a paradigm itself or

just a process of methods with a wide range of typologies in between. Nevertheless, ethnographical research has traditionally consisted of a long-term engagement with the focus of the research, including; (i) wider participant observation and, (ii) more focused data collection such as interviews and focus groups (Hoey, 2008). The former was the primary reason why ethnography was discounted as a methodological approach for this study.

When considering participant observation in a health care setting, it is vital to also consider the ethical dilemmas that may be encountered (Watts, 2011). The aim of this study was to understand experiences of maternity care which encompassed both FGM survivors and health care professionals. Since the desired data consisted of anti-essentialist viewpoints, this would have required observation of all participants who took part in the study which may have been problematic due to the timeframe for the programme. Equally, this would have involved observation of interactions throughout (or at pre-determined points) of the FGM survivors' care episodes. One of the focal points of maternity care is the intrapartum episode of care which can be a fast-paced and unpredictable environment but important when attempting to gain understanding of the participants' experiences. Due to this environmental unpredictability and the potential introduction of other professionals (where needs may quickly change during the intrapartum period) into the care environment, it would be impossible to gain informed consent for participation of all potential participants. Equally, and more importantly, there was potential for severe morbidity and/or mortality outcomes being observed. As a midwife researcher, and governed by a midwifery code of conduct, this may have been a challenge where the clinical situation must be prioritised over the data collection. Parallel to this, the researcher was already embedded into the

maternity care environment which may have impacted on the attempt to narrow the cultural dissonance with the FGM survivors and risk not hearing the 'voice' of the FGM survivors during data collection. Furthermore, such situations exclude FGM survivor participants from the study. As such, ethnography as a methodological approach was discounted due to the potential of such ethical dilemmas.

Summarising phenomenology in the same way as ethnography to explain why this approach was not used poses many challenges; phenomenology is complex and has many variations (Neubauer, Witkop and Varpio, 2019). Phenomenology began as a philosophy that focused on lived experiences (Connelly, 2010) which suggests that it was specifically suited to this study in terms of collecting data on experiences of maternity care. Connelly (2010) explained that there are two main approaches to phenomenological knowledge; (i) descriptive, and (ii) interpretative; both of which consist of the explanation of essences to determine essential structures of individuality. In the early 20th Century, Husserl developed the descriptive approach to phenomenology through eidetic reduction and generalisation (Cunningham, 1976). However, Heidegger rejected Husserl's approach to phenomenology by developing the phenomenological approach that is rooted in an interpretative/hermeneutic style which appears to determine an existentialist and concrete existence (Mohanty, 1978). Whilst these appear to be different approaches to phenomenology, there is one similarity; both appear to be rooted in essentialism which is incompatible with the ontological approach for this study. Furthermore, critical theory and historical realism, that were described in chapter two, posit that reality is not concrete; this appears to be parallel with the knowledge of FGM. The reality around FGM is contemporarily in flux; changing and adapting to reflect the growth of knowledge in this area. So, whilst it was

tempting to attempt to use an interpretative phenomenological approach as a methodology for this study, it appeared to be incompatible with the desired anti-essentialist viewpoints and the ontological perspective of this study.

The ontological perspective identified that the existing reality of FGM is dependent on individual experiences as well as cultural and social backgrounds. As a result, multiple realities may emerge. Furthermore, this study is epistemologically challenging due to the situatedness of the FGM survivors, the health care professionals, and the researcher. For example, the researcher was situated as an insider to the health care professionals but an outsider to the FGM survivors in terms of culture. As a result, there was potential that FGM survivor voices may remain unheard due to cultural dissonance. Therefore, it was crucial that the methodology reflected the situatedness of factors that may contribute to this. This point is supported by the work of Taylor et al. (2016) who explains that qualitative methodology is not just a description of the way in which the research was conducted but how the empirical world was approached by considering the participants of the research as holistic beings rather than reduced to variables.

Hence the methodology followed the emic, or inductive approach where the findings and subsequent theories were based on the data collected from the participants. However, an etic (or deductive) approach was also used when examining the discourse within the literature. Furthermore, it became imperative that the research design did not further marginalise (or silence) the FGM survivors' opinions or

perspectives. As such continual reflection of the research aims was needed during the entire research process to ensure that the unheard was ultimately heard.

5.3 Research design

This study used qualitative methods only to collect and analyse data. The inclusion of quantitative methods was discounted from this study due to the ontological and epistemological foundations as outlined in chapter two. Morgan (2007) pointed out that quantitative research places emphasis on an objective and generalisability of a study's findings, which in this case was not possible and not an aim of this research. The cases of Dirie (1998) and Wardere (2016) highlighted differences in power and emotion which cannot be measured objectively or generalised quantitatively. Yet quantitative data is used by others to collect experiences in maternity care, such as the Care Quality Commission (CQC).

The CQC (2018a) uses statistical data to measure women's experiences of maternity care by analysing data collected via postal surveys. Survey responses identified positive and negative responses to questions. Although this is a useful way to collect large amounts of data, it does not provide depth of data in the same way as qualitative methods. For instance, the most recent report attempted to identify women's differences in experiences, such as their feelings of compassion expressed by maternity health care professionals and involvement in their care. But for this study, it would be impossible to understand the nuances of the differences in experiences without in-depth interviews which helped to provide perspectives on these experiences and outcomes.

The study design was guided by the silences framework which was described in chapter two. There were two distinct phases of this study; one-to-one interviews and focus groups. However, the focus groups were incorporated into stage three of the silences framework which created an overlap and complexity between data collection and analysis. For instance, the one-to-one interviews were analysed iteratively to ascertain the point of data saturation and then further reading and re-reading to identify themes once data collection for phase one was complete. Themes that emerged from these interviews were then utilised to construct the discussion guide for the health care professional focus group which, from the perspective of the silences framework was a phase of analysis. Whilst themes from the FGM survivors' interviews were analysed, new information was obtained during this focus group which provided a different perspective of care for FGM survivors. Themes that were generated from the focus group of health care professionals were then used to construct the discussion guide for the focus group of FGM survivors. Further information on the method for structuring the interview schedule, method for structuring the focus groups, data collection, sampling and analysis is provided later in this chapter.

5.4 Research setting

The aims of this study specifically relate to maternity care experiences of FGM survivors as well and health care professionals providing such care. As such the research setting was within maternity services. The FGM survivors were recruited from one maternity unit in the West Midlands. Consideration was given to the recruitment of the health care professionals group at the same site. But it was concluded that to facilitate protection of the FGM survivor's identities, health care professionals would not be recruited from the same site as FGM survivors; therefore health care

professionals were recruited from the researcher's professional network. During ethics committee discussion, it was agreed that the research site would not be named in this report to further protect the participants' identities.

5.5 Participants

There were two target populations for this study; FGM survivors who were engaged in maternity care and health care professionals who provided maternity care to FGM survivors. Whilst the health care professionals were introduced during the analysis stage, they provided new information which was useful for analysing their perception of FGM survivors as well as their knowledge of FGM within maternity care. Hence these were considered to be participants in the same way as the FGM survivors.

5.5.1. Sample/Inclusion criteria: FGM survivors

The target population for this group of participants was FGM survivors who were engaged with maternity services at the research site; as such, the method of sampling was purposive. The research setting was a large maternity unit in the West Midlands with a birth rate of approximately 8,300 per annum. The population of women who accessed this service was diverse; 40% of the population who accessed this service were from BAME backgrounds. However, only a small proportion of the population were FGM survivors. During the recruitment and data collection period for this study (September 2016 to January 2018) there were 72 FGM survivors who were reported to NHS Digital who accessed FGM services at the research site (72/8300 – 0.9%). Therefore, this represented the target population for this study. The study was introduced to potential participants by midwives working in the clinical area. Participant

information sheets (Appendix II) were available in these clinical areas to provide information to women about the study.

Inclusion criteria for recruitment of this group of participants were grounded in the ethical principles inherent to this study. These consisted of:

- FGM survivors with any type of FGM who were engaged with maternity services. However, it was made clear to women that data collection took place within a few days of their baby's birth (approximately two days depending on their length of stay on the postnatal ward).
- FGM survivors who had planned to or had given birth to a live infant. All modes of birth were included, such as normal vaginal birth, operative vaginal birth or caesarean section birth. Women who had emergency births (such as emergency operative vaginal birth or emergency caesarean section) were not excluded from this study unless there were any adverse outcomes of the birth. For instance, if a woman was transferred to a high-dependency or critical care unit or if the baby was transferred to the neonatal intensive care unit due to poor condition at birth.
- FGM survivors who were able to read, write, speak and understand one of the languages identified for use in this study. These were Arabic, English and French. The WHO (2018) identified 30 countries where FGM is most prevalent. Following a review of the languages spoken in these countries, it was identified that around 1,500 forms of language were spoken; some of these languages have no written value (Sawe, 2018). However, languages most common in these countries were Arabic, English and French. Kroulek (2018) pointed out

that English and French are widely spoken in these countries due to the colonial period when many tribal languages were purged. Furthermore, when reviewing specialist interpretation and transcription companies, many of the tribal languages were not offered. Therefore, it was concluded that due to these three languages being most widely spoken in the areas where FGM is prevalent, these were the languages that should be offered in this study. Consideration was also given to the possibility of illiteracy amongst the participant group. Education may not have been widely available to women in their country of birth. However, it was important that women understood the nature of the research due to the sensitivity of the topic. While it may have been acceptable to the woman for the researcher to assist her in completing the consent form, this may have been deemed as coercive and was therefore not appropriate. However, all of the FGM survivors for this study spoke, understood and were able to write in English.

Furthermore, specific exclusion criteria were identified for this study:

- FGM survivors who were at risk of domestic abuse. Cook and Bewley (2008) identified that domestic abuse may manifest or worsen during pregnancy and 5.4-27.7% of women may have already experienced domestic abuse. Gracia (2004) uncovered that only 2.5-15% of women may report domestic abuse. However, questions surrounding women's home situations are discussed

routinely by midwives at three points during their maternity care[24] which may identify women who are subject to domestic abuse.

- FGM survivors who had experienced a miscarriage, an inter-uterine death[25], stillbirth or neonatal death. During discussion with the ethics committee, it was agreed that FGM survivors who had experienced any of these were not suitable to be approached to take part in the study due to the potential distress that they would already be experiencing.
- FGM survivors who were not able to communicate in any of the languages identified in the inclusion criteria.

5.5.2. Sample/inclusion criteria: Health care professionals

The target population for this focus group was health care professionals who were involved with the delivery of maternity services for FGM survivors. The group consisted of midwives and obstetricians since both of these groups provide care to FGM survivors but from different perspectives. For instance, midwives plan and provide routine care whilst obstetricians plan and provide care when women are aligned to specific care pathways that require obstetric intervention. Since FGM is considered to be high risk requiring obstetric intervention (RCOG, 2015), it was important to include this group in the focus group discussion. The construction of this focus group followed Krueger and Casey's (2015) method for the design and construct of focus group discussions.

[24] Women are routinely asked about their home situation at their initial booking appointment, during their pregnancy (which may be between 20 and 34 weeks of pregnancy) and during their postnatal checks.
[25] Inter-uterine death is when fetal death is confirmed via ultrasound scan before the commencement of labour.

Krueger and Casey (2015) proposed that the purpose of the focus group is driven by the study aims, the information required and the participants having a degree of knowledge about the subject. Since the aim of the focus group was to explore health care professionals' views of the responses from the FGM survivors, as well as their views on the provision of care to FGM survivors, the inclusion criteria consisted of:

- Employed to work in (or alongside) maternity services with FGM survivors and/or experience of providing maternity care to FGM survivors
- Band six or seven midwife
- Grades ST1 to ST6 obstetric trainee
- Provided care to FGM survivors at the time of data collection or within the year previous to data collection.

There were exclusion criteria for this group of participants:

- Employer is not the research site where FGM survivors access maternity care
- Midwife of band eight or above
- Obstetrician of grade ST7 or above.

However, it was noted that other groups were often involved in the care of FGM survivors during their maternity care episode. HM Government (2014) suggests that women also access voluntary sector organisations for help and support during this time. Equally, RCOG (2015) provide a list of services for women to be signposted to, however, there are no explicit recommendations for third sector support for FGM

survivors. Nevertheless, the target population for this group was widened to include other support workers who provide care to FGM survivors during their pregnancy.

The inclusion criteria met the recommendations for homogeneity as described by Krueger and Casey (2015), but power and hierarchy were significant considerations for this focus group. Begley (2002) conducted a mixed-methods study to ascertain the hierarchy in midwifery and found that midwives above the seventh grade were considered to be an elitist group who were quick to criticise or reprimand. Since there was risk that the inclusion of this group may affect the power dynamics of the focus group, no midwives above band seven were included. The same method of selection was used for obstetricians. Nevertheless, there was further consideration of the power dynamic between the midwives and doctors.

Reiger (2008) highlighted the traditional challenges in the relationship between midwives and obstetricians which can result in professional conflict which is distorted by domination. Yet the results of Reiger's (2008) work suggests that the conflict is of institutional creation where decision-making remains hierarchical. However, the results of Larsson et al. (2009) study suggested that the dynamics of the relationship between midwives and obstetricians has changed since the advent of women obstetricians as well as younger doctors having more trust and respect for experienced midwives' opinions. Nevertheless, there was further risk that power in the focus group may have imbalanced towards the midwives if all the obstetricians were lower grade junior doctors. Therefore, the participants were carefully selected to provide a mixture of grades and experiences for both midwives and obstetricians.

5.6 Recruitment

There were two recruitment methods used for this study; FGM survivors were recruited purposively and health care professionals were recruited via convenience sampling. This section provides an explanation of the processes of recruitment for both cohorts.

5.6.1. Recruitment of FGM survivors

FGM survivor participants were purposively recruited to this study; with the application of the inclusion and exclusion criteria, the target population became 45 potential participants. To facilitate recruitment, midwives who were employed in the clinical areas where the potential participants received care were furnished with information about the study to provide to FGM survivors. The study was discussed with midwives in the clinical area so that they understood the nature of the study and the process of data collection. In a study where potential participants are considered particularly vulnerable, there is a risk that many who initially express an interest in taking part may ultimately decide not to take part. Steinke (2004) pointed out the difficulties involved with recruiting and retaining vulnerable participants within a study; particularly when research is conducted within the clinical sphere of practice of a researcher and the current care environment of the participant as well as participant expectations during the study. The recruitment and retention of FGM survivor participants for this study was particularly challenging and is discussed further in the limitations section in chapter nine. The final sample size was 20 participants who were all fluent in the English language. As such, there was no need to employ interpreters during the participant interviews or translators during the transcription process. Table 3:5 presents the characteristics of the FGM survivor sample.

When potential participants expressed an interest in taking part in the study, their contact details were passed to the researcher, with their consent, so that the researcher could discuss the study with them and gain their consent for participation. FGM survivors who wished to proceed with participation were then given consent forms to complete by the researcher. However, the signing of the consent form did not take place until the day of the interview to ensure that participants had sufficient time to consider their consent to participation. The average time taken from receiving the information and consent form to signing the consent and participating was 24 hours.

5.6.2. Recruitment of health care professionals

The researcher's professional network was aware of this study during the planning stage. As a result, the health care professional participants all requested to take part in this study; this included one member who was recruited from a voluntary organisation.

Table 4:5 presents the sample of health care professionals who took part in the focus group. Each member of the focus group was given information about the study and a consent form to complete. The same process of consent that was used for FGM survivors was used for the focus group; consent forms were provided but completion of the forms was not required until the same day that the focus group took place. All participants who were invited to participate took part in the focus group and none withdrew following participation.

Table 3:5 Sample of FGM participants

Study ID	Country of Origin	Type of FGM	Type of Birth
FS01	Yemen	2	Normal
FS02	Yemen	1	Normal
FS03	Somalia	1	Caesarean Section
FS04	Somalia	3	Normal
FS05	Somalia	1	Forceps
FS06	Yemen	2	Ventouse
FS07	The Gambia	2	Ventouse
FS08	Somalia	3	Normal
FS09	Yemen	Unknown	Normal
FS10	Yemen	1	Normal
FS11	Egypt	1	Caesarean Section
FS12	Eritrea	2	Caesarean Section
FS13	Sudan	3	Normal and deinfibulation
FS14	Somalia	3	Ventouse and deinfibulation
FS15	Somalia	3	Normal and deinfibulation
FS16	The Gambia	2	Normal
FS17	Eritrea	3	Ventouse and deinfibulation
FS18	Sudan	Unknown	Normal
FS19	Sudan	2	Ventouse
FS20	Somalia	3	Caesarean Section

Table 4:5 Sample of health care professionals

Study ID	Profession	Grade	Ethnic background
HCP01	Midwife	6	Caucasian
HCP02	Midwife	6	BAME
HCP03	Doctor	ST6	BAME
HCP04	Midwife	7	BAME
HCP05	Doctor	ST3	BAME
HCP06	Doctor	ST1	Caucasian
HCP07	Midwife	7	Caucasian
HCP08	Voluntary sector	N/A	BAME
HCP09	Midwife	6	BAME

5.7 Pilot study

The initial interview schedule for FGM survivors was derived following the literature review. Questions one to three aimed to challenge the ethnocentrism that emerged from the literature and was an attempt to balance the power dynamic between the researcher and FGM survivor. Questions four to seven were specific questions on maternity care which aimed to explore participants' experiences during access to maternity services. These questions were derived from the critique of clinical guidance and health care educations with an attempt to reveal experiences based on health care professional's guidance and education. Question eight was an attempt to expose FGM survivors' feelings around recording data on FGM survivors. Since this was a relatively new national dataset that was introduced without FGM survivor's input, the rationale for this question was to gain some views on this from the FGM survivors themselves. Question nine was an open-ended question that aimed to provide a platform for FGM survivors to express or share information that the previous questions had not covered.

1. *Does your community support circumcision of females?*
2. *How do you feel about western society's views of female genital cutting?*
3. *How do you feel when someone uses the term FGM? (Does this reflect your own feelings/beliefs?)*
4. *Tell me about your feelings when you discovered that you were pregnant.*
5. *Tell me about the support you received during your pregnancy.*
6. *Tell me about your labour experience. (Particularly about the care you received from doctors and midwives).*
7. *If your circumcision was discovered when you were in labour, tell me how you felt about this.*
8. *Did you know that midwives have a duty to report all cases of female circumcision as part of national data collection and safeguarding children? How do you feel about this?*
9. *Is there anything that you would like to tell me about your care in the maternity services?*

A pilot study was conducted during the first four FGM survivor interviews. The intention of the pilot study was to ascertain whether the questions resulted in data that was of sufficient quality. During initial comparison and analysis of these first four interviews, it became apparent that pre-pregnancy experience had a significant effect on the FGM survivor's initial experience of maternity care due to previous experiences with health care professionals. For instance, question two generated a lengthy discussion around pre-pregnancy deinfibulation and the sub-standard counselling received which led to a discussion around PTSD. Yet, this discussion answered questions one to four. Following this interview, two further participants gave similar responses which identified the importance of pre-pregnancy care related to FGM and its impact on the FGM survivor's expectations of health care professionals in maternity services. However, the following five questions generated data which was not of sufficient quality. For instance, question five generated brief answers such as 'yeah, it was fine' (FS04) and question eight generated answers such as 'yeah, I was told that but it's fine' (FS03).

Following the first four interviews, the list of questions became a discussion guide (Appendix VI) rather than rigid focus on a prescribed list of questions. As a result, the interview discussions became more natural and expressive which enabled the participants to provide information on elements of their care that may not have been openly discussed or pursued by health care professionals during their maternity care. The discussion guide consisted of areas for exploration but included prompt questions that were based on the original question list. The prompting questions aided the collection of data where specific issues were not covered by the natural conversation.

5.8 Data collection and analysis

Data collection was structurally aligned to the silences framework. There were three specific points when data was collected, however data analysis was conducted throughout these stages to enable construction of discussion guides for subsequent data collection episodes. Serrant-Green (2011) pointed out that the phases of analysis were not intended for data collection use and Janes et al. (2018) concurred and argued that this stage is only appropriate for analysis and not collecting data. However, at phase two, the second participant group was introduced. Therefore it was inevitable that new data would be generated at this point. As such, data collection became symbiotic to data analysis. Figure 10 illustrates the points of data collection and analysis intrinsic to stage three of the silences framework.

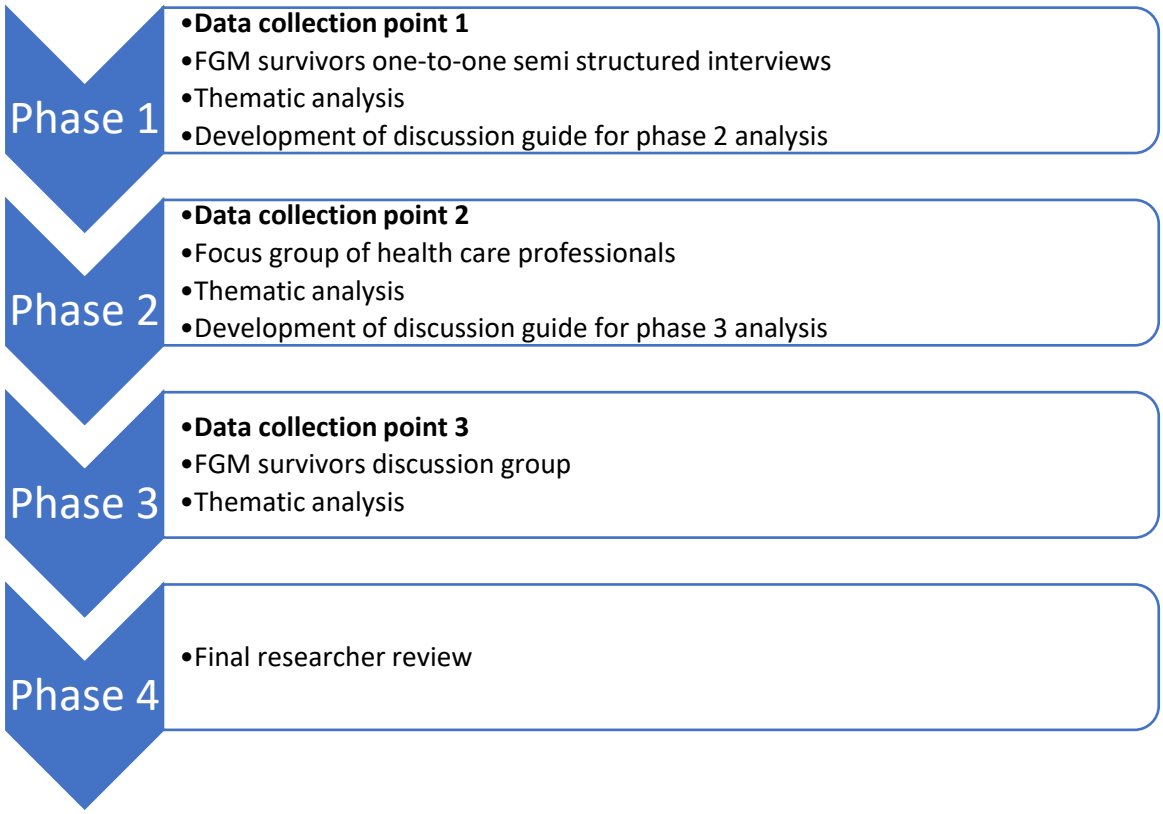

Figure 10: Silences Framework: Stage Three: points of data collection and analysis

Following the pilot study, the data collection tools for all three data collection points became discussion guides. During each data collection episode (one-to-one interviews and focus groups), discussions were recorded onto a digital audio device which was password encrypted to protect participants' data. The following sections present the data collections points and the construction of data collection tools for each subsequent stage of analysis.

5.8.1. Data collection point one: FGM survivors' interviews

Data collected at point one took place immediately following discharge from the inpatient maternity service. Although the FGM survivors were still engaged with maternity services, the data collected was a reflection of their maternity care from initial

contact with maternity services to the point of inpatient discharge; the full pathway of maternity care for FGM survivors can be found at Appendix XIII. The rationale for this was to enable the FGM survivors to reflect on their whole episode of care during their access to maternity services. However, collecting data retrospectively can lead to missing information that may be crucial to the analysis and results (Weinger et al., 2003; Powell and Sweeting, 2015). Nevertheless, only one interview was conducted with the FGM survivors as this would be less intrusive and enable them to reflect on specific points in their care without the need for additional interviews. This approach supported the perceived vulnerability of the FGM survivor participants.

This is supported by the following objectives for this study:

- Exploring the experience of a UK maternity service for FGM survivors
- Exploring the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors
- Critically examining the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally
- Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.

There were three specific areas of focus within the discussion guide for the one-to-one interviews; (i) experiences of care prior to pregnancy, (ii) experiences of care during pregnancy, and (iii) experiences of care following the birth of their baby. However, there were discussion prompts for each of these which encouraged exploration of each

of these key time points; however these prompts were not required for every interview (see Appendix VI for this discussion guide).

The amendment to the data collection tool generated deeper, individualised experiences which elicited wider experiences that impacted on their maternity care. For instance, introducing words such as ‘feelings’ in conjunction with ‘experiences’ appeared to invoke discussion of existing mental health issues such as depression and anxiety; the original list of questions did not encompass any questions surrounding personal feelings.

During the pilot study, the interviews did not exceed the 30 minutes which was agreed with the ethics committee. Yet when using the discussion guide, the interviews continued to an average of 45 minutes; with many FGM survivors requesting to continue with the interviews when the time exceeded 30 minutes. Dicicco-Bloom and Crabtree (2006) point out that the length of the interview should usually last for a minimum of 30 minutes; Fox (2009) further stated that good quality data is collected when participants are given the opportunity to discuss their experiences without time constraints.

Data saturation for this phase was based on thematic saturation which is achieved when no new themes emerge (Patel, 2015). Power was a strong theme in the literature which was symbiotic to cultural sensitivity as well as communication. Therefore saturation was based on these themes. Whilst it can be argued that data can never be saturated in qualitative research (O’Reilly and Parker, 2013), maintaining a record of

such themes helped to identify when no new information was collected based on these themes. Guest et al. (2006) described this audit of themes as a codebook; once no new codes were generated, saturation had occurred. Following 17 interviews, no new data was collected but to test whether data saturation had occurred at this point, a further three interviews were conducted. Once data saturation was achieved with the FGM survivors' interviews at data collection point 1, thematic analysis was conducted and themes were generated which informed a discussion guide for a focus group of health care professionals.

5.8.2. Analysis

Twenty one-to-one interviews of FGM survivors were completed over a 15-month period (September 2016 to January 2018). Following each interview, recordings were transcribed by the author which took an average of four hours per interview recording. Some consideration was given to employing a professional transcription company to transcribe the interviews, but it was believed to be beneficial for data immersion for the author to complete the transcriptions. Once all transcriptions were completed, these were read and re-read to identify common themes within the data.

Willig (2013) pointed out that the coding is aligned to the research aims. The research aim pertinent to this collection of data was the maternity experience of FGM survivors. The subsequent data that was elicited from the FGM survivors was instinctively (or unconsciously) separated into experiences of five specific time periods. This was useful in deconstructing each transcript and looking at experiences for specific time periods. Each of these time periods were then coded in alignment of the aim.

5.8.3. Coding strategy

For phases one to three (or data collection points one to three), data was analysed thematically. Willig (2013) stated that thematic analysis plays an important role in first recognising and organising patterns in the content of the qualitatively collected data. As such, thematic analysis for this study was based on Braun and Clarke's (2006) method.

Braun and Clarke (2006) described thematic analysis as a six-stage approach and since thematic analysis was independent of theory and epistemology (Braun and Clarke 2006, p78), it provided 'theoretical freedom' in analysis for this stage (Willig, 2013, p180). Braun and Clarke's (2006) six stage approach consisted of:

- Data familiarisation which consisted of transcribing the collected data as well as incorporating field notes into the transcripts and reading and re-reading the entire dataset
- Generating initial codes which encompassed interesting or compelling features across the entire dataset which facilitated the collation of data to each of these relevant codes
- Searching for themes which incorporated collating codes into potential themes and gathering the data into each of these potential themes
- Reviewing the themes on two levels; by comparing the codes with each of the themes in relation to the coded extracts and then across the entire dataset. Then generating a thematic map in order to map the themes across the data.

- Defining and naming the themes by further analysing each specific theme to generate clear definitions across the whole data set to provide clarity of the overall data
- Whilst producing the report was the final stage of Braun and Clarke's (2006) analysis, this was completed in two stages. The first stage was to provide a discussion guide for stage two and subsequently stage three of analysis, then using compelling and vivid quotes extracted from the analysis to strengthen the presentation of the findings.

Since qualitative data was collected during this study, initial analysis began at the beginning of data collection. This also facilitated in shaping the discussion guide for the FGM survivor interviews following the pilot study. Furthermore, since all the data was collected verbally, and recorded onto an audio device, transcribing such data was an extremely useful exercise in familiarisation (Braun and Clarke, 2006). Furthermore, during interviews, some field notes were recorded which provided context to nuances of speech as well as nonverbal communication. As such, these were incorporated into the transcribed interviews which provided a verbatim account of experiences. At the end of this stage, initial codes were generated.

The coding was completed manually by systematically identifying aspects of care throughout each transcript. Braun and Clarke (2006, p89) describe coding as either 'data driven' or 'theory driven'. However, for this study the coding was data driven to capture the 'voices' of the FGM survivors and health care professionals for

construction of the discussion guides in phases two and three of analysis respectively. Appendix XI provides an example of coding.

Each transcript was manually coded in Microsoft Word which enabled some texts to be coded multiple times for different themes. Once initial coding was complete, themes were generated. Once themes were refined, these were then used to construct the discussion guide for health care professionals which marked data collection point two and phase two of analysis.

5.8.4. Constructing the discussion guide for data collection point two

The aim of phase two of the analysis was to ratify, refute and/or challenge the interpretation and findings from phase one of the analysis (Serrant-Green, 2011). As such, the discussion guide for phase two was constructed from the initial sub-themes and themes as well as compelling responses that were interpreted from phase one of the analysis. This resulted in questions and discussion points that were different from those generated for the discussion guide used during the one-to-one interviews with FGM survivors. Nevertheless, the discussion points remained focused on the experience of care for FGM survivors but included the experience of providing care for FGM survivors. However, there was potential for new data (or voices) to be heard for this phase due to discussion points being generated from novel data collected from FGM survivors. Section 6.3 presents the development of the discussion points following the initial analysis of data from phase one.

5.8.5. Data collection point two: Health care professional's focus group

This focus group marked phase two of the analysis but encompassed the collection of data from the health care professionals. The discussion guide was derived from the responses provided by the FGM survivors during the one-to-one interviews. Therefore the focus group discussion encompassed five specific areas that were dictated by the FGM survivor experiences. These were (i) care for FGM survivors prior to pregnancy, (ii) care for FGM survivors at the beginning of pregnancy, (iii) care for FGM survivors during pregnancy, (iv) care for FGM survivors during labour and birth, and (v) care for FGM survivors in the immediate postnatal period.

In parallel to the discussion guide for the one-to-one interviews, the focus group discussion guide included discussion prompts where specific points required clarification. However, the anonymised transcripts were also available during the focus group to ensure that the researcher had interpreted the themes correctly and appropriately. Ground rules were used for this period of data collection which consisted of:

- Re-confirm consent
- Phones to be switched to silent
- There are no right or wrong answers
- Members to speak one at a time with no interruptions
- Do not identify anyone (including patients, members of staff or any member of the public) during this discussion
- Each member of this group is to be respectful of each other
- The discussion during this focus group remains confidential. Repeating or identifying members of the focus group is a breach of that confidentiality
- During this discussion, there may be some information discussed that is distressing. In such circumstances, you may leave the room. Please indicate

if/when you would prefer to exclude yourself from the discussion and the recording will be temporarily paused to allow you to exit.

- Thank you for taking part in this discussion group

Following discussion of the focus group ground rules, each participant was given an identification number to state prior to their contribution to the discussion. This aided transcription due to the researcher facilitating the discussion alone. However, this number differed from their study identification number. This was to ensure that members of the group were not able to identify each other where quotes used in the final report required study identification numbers. The discussion during the focus group consisted of questions that were generated following analysis of the FGM survivors' interviews (Appendix VII). The discussion guide consisted of five different points of the maternity care journey that were described by the FGM survivors. However, the discussion guide included supplementary questions to further probe the group when the discussion did not elicit responses around these key areas.

This discussion guide supports the following objectives for this study:

- Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors
- Critically examine the education and guidance widely available to health care professionals on FGM
- Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally
- Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.

The focus group of professionals was 60 minutes in duration which was agreed during the ethics committee review. The discussion was audio recorded using the same equipment used during the one-to-one interviews with the FGM survivors. Transcription of the focus group recording was completed over three days; in total, it took 12 hours to fully transcribe the focus group discussion. Following transcription, data was analysed and organised into themes which were used to construct the discussion guide for the focus group of FGM survivors.

5.8.6. Construction of the discussion guide for data collection point 3

The aim of data collection point three (or phase three of the analysis) was, in parallel with phase two, to ratify, refute and/or challenge the interpreted findings thus far (Serrant-Green, 2011). As such discussion guide for this phase was constructed in the same way that the discussion guide for phase two was constructed. The transcript of the focus group was coded and analysed and new information that was obtained was used to construct the discussion guide. Compelling quotes were also used in the same way as were used in the construction of the discussion guide for phase two. Since new information was included in this discussion guide, the discussion points were different again from those used in phases one and two but continued to focus on the care of FGM survivors in maternity services. The development of this discussion guide is presented in section 6.6.

5.8.7. Data collection point three: FGM survivors discussion group

Data collection point three (or phase three of the analysis) consisted of FGM survivors who considered the findings of the focus group of health care professionals. Whilst

there were just two members of this group, this generated discussion which contributed further to the silences dialogue as well as gathering further primary data regarding the FGM survivors' views of the health care professionals' education and statutory accountability and responsibility to the NMC as well as the General Medical Council (GMC).

The FGM survivors who took part in the one-to-one interviews were all invited to return to take part in the focus group. However, due to family commitments, only two FGM survivors returned to take part. This aim of this group was to review and explore the findings from the focus group of health care professionals. The same identification numbers were used from the original one-to-one interviews so that the participant responses were traced through the analysis. In parallel with the focus group of health care professionals, the focus group transcript was available to ensure that the researcher has accurately interpreted the findings for discussion.

In parallel to the health care professional focus group, the same ground rules were established for this group. This discussion was completed in 50 minutes; see Appendix VIII for the FGM survivor's discussion guide.

The discussion guide for FGM survivors supported the following objectives for this study:

- Explore the experience of UK maternity services of FGM survivors
- Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors

- Critically examine the education and guidance widely available to health care professionals on FGM
- Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally
- Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.

Following this discussion, transcription was completed in the same manner as the health care professionals' focus group. The audio recording of this group was transcribed in the same way as the health care professional focus group; this took a further six hours to transcribe. Following the transcription of this focus group discussion, the same coding strategy that was described in this section was used to elicit themes from the data to take forward to the final researcher review for phase four of the analysis.

5.9. Phase four analysis

The aim of this phase of analysis was determine whether silences exist across the entire dataset. In this study, language and the use and implication of terminology were specific aims, hence analysing words and statements used across the data was an important aspect of this study. Yet to develop context to such words and statements across the data, the entire data collection needed to be completed (as described in the preceding sub-sections of section 5.8). This enabled comparison of words, statements

and their implication in the relationship between the FGM survivors and health care professionals.

The discursive objects (i) power, (ii) vulnerability and (iii) agency that were identified during the critical review of literature appeared to frame the knowledge and understanding of FGM in the texts. Therefore, Foucault's (1977) work on societal power appeared to be a valuable way to interpret power and vulnerability in the collected data.

5.9.1. Justification for applying Foucault's theory of power to the data

In Foucault's (1977) work on discipline and punishment the aim was to deconstruct power and how power, or the abstract notion of power, preserves social cohesiveness. Foucault (1977) expanded on the eighteenth century work of Bentham's construct of the panopticon and argued that this concept in fact extended beyond the prison; it exists in an abstract way in everyday life where all individuals internalise authority to maintain social order. Foucault (1977) further argued that this 'modern social prison' was an effective way of wielding power and control which is accomplished via a three pronged approach; (i) surveillance, (ii) normalisation and (iii) examination; these are discussed further in chapter seven. Foucault (1977) posited that power itself is difficult to identify since it is widespread and diffused in society. However, Foucault (1977) position was that power is confined to knowledge and those who hold the knowledge, ultimately hold power. As such, those who 'create knowledge', who Foucault (1977) terms as 'thought leaders' contribute to the genealogy of the modern soul. In other words, throughout history society is moulded by knowledge through a narrow cultural

perspective on what it is to be human. But this knowledge has been collected from, or generated by, extremely narrow perspectives on what is deemed ‘normal’ in western society. Foucault (1977) further stated that these narrow perspectives were based on the normality of white western males due to these being the primary thought leaders in social and medical sciences in history. As such, society is trapped in the panopticonic mould of a pre-existing belief of what a person should be or should believe. This same argument can be applied to FGM survivors’ experiences of maternity care and health care professionals’ experiences of providing such care; particularly in terms of cultural dissonance and understanding of cultural sensitivity intrinsic to FGM survivors. However, in this case, power can be both overt and covert (or silent). For instance, HM Government (2003) is overt in wielding power in the way FGM is perceived and understood yet CQC (2018b), NMC (2018a) and RCOG (2015) covertly wield such power as to control the way health care professional’s provide care to FGM survivors.

However, Foucault did not construct a predetermined framework for conducting analysis using his theories, instead he described it as a trail on which to divert (Rouse, 2005). Therefore, a systematic approach was required to isolate the dominant discourses within the interpreted overarching themes and then apply Foucault’s theory of power to interpret silences from the data. The entire pathway of analysis is illustrated in Figure 11.

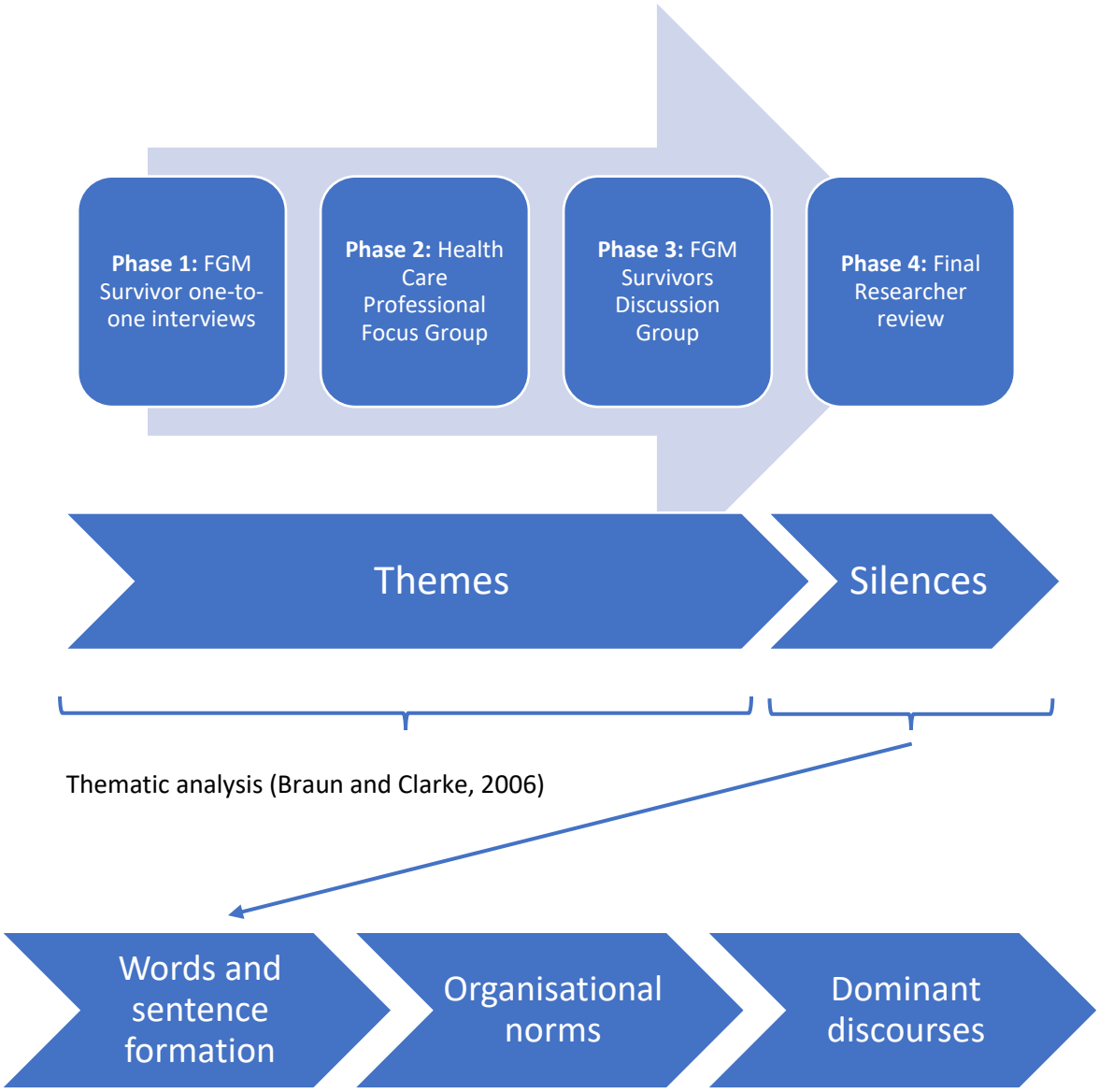

Figure 11: Pathway of analysis

5.9.2. Process of phase four analysis

The aim of the final phase of analysis was to analyse the words used by the participants, the structural norms of maternity services and isolate the dominant discourses throughout the data collected in the interpreted themes. The objective of this phase reflected the discursive objects of power and vulnerability that was interpreted from the literature review. As such this phase of analysis was to ascertain whether power exists in the maternity care of FGM survivors and if so, who inhabits the positions of power. Conducting this phase of analysis and then applying Foucault's theory of power, enabled an elicitation of the silences across the data. The following sections present the steps taken during this process.

(i) Words and sentence formation

The first step was to revisit each of the transcripts with the text arranged in the interpreted themes. The words that were used to create sentences were analysed and how these were employed to create meanings and opinions. Erlingsson and Brysiewicz (2017) describe this process as content analysis and a practical way of providing a voice to the voiceless. This was achieved in the following steps:

- In the data that was grouped into each overarching theme, the first step was identification of words that describe experiences, feelings and processes.
- The next step was to analyse the context in which the words were used. For example, when identifying the word 'important', there were numerous contexts to consider;
    - What is important?
    - Who is it important to?
    - Why is it important?

- When is this important?
- How is this important?

Analysing the context of the words was an important step in understanding the views and opinions of the participants' experiences.

These words were then grouped together within each overarching theme to provide context to feelings and experiences within each theme. At this stage, Foucault's theory of governmentality was applied to these feelings, experiences and processes to explore whether there was an element of self-government embedded in these experiences.

(ii) Organisational norms

The next step was to determine the norms of the organisations which provide maternity services for FGM survivors. The objective with this part of the analysis was to understand how the words and sentences that described the experiences, feelings and processes reflect the structural norms within maternity services.

Once the organisational norms were determined, Foucault's theory of the social panopticon was applied to these to explore whether there was intrinsic power and/or regulation that was embedded in maternity services for FGM survivors.

(iii) Isolating dominant discourses

When considering which discourses were dominant in maternity care experiences, it was important to distinguish between dominant and subordinate discourses since these might have an impact on the interpretation of silences. For instance, Allen (2007) suggested that dominant discourses generally relate to power and 'norms' of a given group or society. As such subordinate discourses might be marginalised due to occupying a different norm to the dominant group; this was also reflective of Noelle-Neumann's (1993) spiral of silence theory. In this study, the dominant norms relate to the discourses in maternity care that support power and, as acknowledged by Allen (2007), support political interests and authority. This was particularly important in this study in terms of care provision that was politically driven from both a maternity care perspective and a legal perspective.

The process of isolating dominant discourses in the transcripts consisted of:

- Comparing the context of the words used in step (i) to the organisational norms in step (ii) to explore whether the words and context used were related to service provision.
- Identifying the positions and subjectivities of people involved with the provision of maternity care and cross-referencing these subject positions with the words used, the context of the conversation and the organisational norms that were reflected in the conversation. This was an important step in identifying whether there was power intrinsic to subject positions in the discourses and whether this power provided dominance to specific positions.

On completion of each of these steps, the findings are presented as silences heard from the data.

5.10. Ethical considerations

The ethical considerations for this study were to protect, as far as was possible, the study participants from harm. I therefore employed a methodical approach to ensure that I had considered and addressed both apparent and potentially concealed vulnerabilities. This section provides the ethical considerations that were pertinent to this study and the steps taken to mitigate against any risk.

5.11.1. Pregnancy and childbirth: FGM survivors

According to Astrup (2018), FGM survivors are considered to be a marginalised population; FGM is also considered to be a sensitive topic (Norman et al., 2009; National Institute of Health and Care Excellence (NICE), 2018; RCOG, 2015; WHO, 2018). As such, the FGM survivors who participated in this study were considered to be vulnerable. Therefore, the protection of these women due to their vulnerabilities within this research was paramount. Furthermore, the FGM survivors had recently given birth and van der Zande et al. (2017) also described this group of participants was considered to be vulnerable. As such, there was potential that the FGM survivors may have been exposed to stressful or difficult conversations during the research. As a midwife of ten years, I have experience of providing care for women living with FGM and was therefore in a position to act as counsellor for any participants who experienced distress through the interview process. McCosker et al. (2001) supported the view that the researcher can assume the role of counsellor especially in cases

where sensitive issues are the focus of a study. However, I did not believe that it was appropriate for me to act as counsellor in this study due to inherent cultural differences between me and the participants as well as my position as an outsider to FGM (Olohan, 2001). Therefore, the participants were given a list of organisations that provide specialist support and counselling to women who have experienced and live with FGM. All of these were included on the participant information sheets (Appendix II). I contacted the FGM survivors two days following each interview to ensure that the interview process did not raise any issues for which the FGM survivors may need additional support.

5.11.2. Communication and language barriers – FGM survivors

It was anticipated that many of the participants would have little or no understanding of the English language; communication was therefore another key ethical consideration in this study. Therefore, in order to mitigate against this risk and ensure that women fully understood the rationale for the study as well as their right to withdraw up to the point on anonymization of data, all invitation letters, participant information sheets and consent forms were translated into Arabic and French as well as providing an English copy.

There was potential for some of the women participants to not understand or speak English. Therefore, contact was made with professional interpreting services to facilitate interpretation during the interviews of women participants. Nevertheless, during recruitment and data collection, none of the women participants had any

difficulty with speaking or understanding English so engaging professional interpreting services was not required.

5.11.3. Ethical considerations: Health Care Professionals

Ethical considerations for health care professionals were also important and carefully considered in this study. The role of the health care professional focus group in this study was to discuss the findings from the data collected from the FGM survivor participants. The discussions could potentially contain distressing information so it was crucial to ensure that there was provision for the protection of the health and social care professionals who participated in the focus group. At the beginning of the focus group, ground rules were discussed (see section 5.7). Furthermore, an element of the participant information sheet for the focus group was the same list of support groups and contacts that provided services for women who had experienced FGM (Appendix II). One service, Birmingham and Solihull Women's Aid, was local to the research site which provided support and guidance for FGM survivors as well as health and social care professionals.

5.11.4. Confidentiality

Protection of the confidentiality and anonymity of the FGM survivors and health care professionals and any information that they disclosed during the data collection process was of paramount importance. The participant information sheets provided all participants with information about the study, including details regarding their confidentiality and anonymity. However, as identified in the literature review, women

(or members of their wider family) may have supported the practice which may have led to a potential risk to a female infant. Therefore, a clause was added to both the participant information sheet as well as the consent form which indicated that complete anonymity was not possible if there was any implication that an individual may have been at risk of significant harm. As an NHS employee and a researcher working within an ethical code of practice, there is a legal and professional duty to disclose information if there is a suspicion that a child or infant is at risk of significant harm; whether that risk is related to FGM or otherwise.

The one-to-one interviews with the FGM survivors involved collecting particularly sensitive data such as pre-existing mental health issues, experiences of care that were particularly negative and other life experiences that affected some FGM survivors' impression of health care professionals. In parallel, data collected during the health care professional focus group was considered to be sensitive due to the views expressed during the discussion; all of these are voiced in chapters six and seven.

Therefore, the one-to-one interviews took place in a room at the research site that was close to, but not directly adjacent to, the maternity ward where the women were recruited. The room was further secured by a coded lock and all women were given the option to have the room locked during their interview; all women accepted this. The focus group took place in a secure room that was at the research site. During the focus group, no other person had access to the room.

All data was collected onto a digital audio-recording device which was encrypted and password protected. The password was changed following each interview and not recorded in any other medium in order to prevent accidental disclosure. Following each interview, the audio recording was transcribed and then the recording was immediately deleted to prevent further accidental disclosure. Following the focus group, the recording was transcribed in the same manner. All transcripts were retained on an encrypted USB drive and held at the research site in a locked office in a locked cupboard to maintain safety and confidentiality of the data.

The research site, other than geographical area, is not named in this thesis. During the ethics committee review, there was agreement to anonymise the research site to aid in the protection of the FGM survivors' identity. However, in parallel, the health care professionals were not selected from the same site as the FGM survivor group. The percentage of FGM survivors accessing maternity services at the research site was 0.9% of the total number of women accessing maternity care and the care of these women is delivered by a small group of health care professionals. Therefore, the likelihood of FGM survivors being identified through themes within the discussion guide for phase two was potentially high. In order to mitigate against this potential risk the health care professionals were recruited via personal networks who did not provide any care at, or have any affiliation with, the research site.

5.11.5. Voluntary participation

Participants in both groups were fully aware that their participation was voluntary, and they could withdraw from the process, even if they had already consented. However,

this withdrawal only extended to the point prior to anonymisation of the collected data; this was pointed out in the study materials. It was further necessary that any of the participants in either participant groups were not, or did not feel, coerced into taking part in the research.

5.12. Potential and actual risks

Conducting research with a marginalised and perceived vulnerable population, there were potential risks that required actions against which to mitigate. However, during the course of the study, management of these risks required a systematic approach. Therefore, in order to mitigate against potential risks, as well as provide action plans to alleviate actual risks, a risk register was maintained throughout the study. Whilst limitations were also identified during this study, these are presented in chapter seven. The risk register encompassed all areas of the research and included:

- Ethics approvals
- Study start
- Recruitment
- Study support
- Environmental resource

Kuchta and Ptaszynska (2016) identified a gap in qualitative research whereby a risk register provided a framework to identify and monitor risks. As a midwife working within the governance field of maternity, this was a familiar concept and became a systematic approach to identifying, monitoring and minimising risks within the study. The risk register can be found at Appendix XIV.

5.13 Chapter summary

This chapter has presented the methodology associated with the ontology and epistemology of this research which has identified the methodological perspective as including both emic and etic approaches. The research design has been described as well as the methods used to identify the participant samples and how the data was collected. A description of the phases of analysis has been presented in this chapter as well as the ethical considerations and the potential and actual risks of the study.

The following chapter presents the data and the resulting findings that were elicited using the methods in this chapter.

CHAPTER SIX: VOICING SILENCES (STAGE THREE)

PHASES ONE TO THREE: ANALYSIS

6.0 Introduction

This chapter presents the results which were interpreted from the collected data. The data herein was derived from participants' individual personal and professional experiences of receiving and providing care respectively.

The construction of this chapter was led by the phases of analysis that are embedded in stage three of the silences framework. Firstly, the one-to-one interviews with FGM survivors are analysed and themes are generated from this initial analysis, secondly the focus group of professionals is analysed and themes are generated and thirdly the group discussion of FGM survivors is analysed and further themes generated. This then leads to a final researcher review and analysis of the discourses. Chapter seven will present the final researcher review of the entire data.

6.1 Phase One: FGM survivor one-to-one interviews

Phase one marked the analysis of the twenty one-to-one interviews with FGM survivors. There was continual referral to the aims relevant to the FGM survivors throughout this phase of analysis:

- *What is the maternity care experience of FGM survivors in a UK maternity service?*
- *Does health care professionals' knowledge of FGM have any impact on the care that FGM survivors receive in maternity care?*
- *Does language and communication affect the care that FGM survivors receive?*

Equally, the objectives relevant to the FGM survivors throughout this phase were:

- *Explore the experience of UK maternity services of FGM survivors*
- *Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors*
- *Critically examine the education and guidance widely available to health care professionals on FGM*
- *Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally*
- *Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.*

During the semi-structured interviews, the discussion was sub-divided into three sections: (i) experiences of care prior to pregnancy related to FGM, (ii) experiences of care during pregnancy and (iii) experiences of care following labour and birth. During the interviews, five episodes of care were identified which reflected on the natural journey through maternity care. These consisted of:

- Experiences prior to pregnancy
- Experiences at the beginning of pregnancy
- Experiences during pregnancy
- Experiences during labour and birth
- Experiences in the 48 hours following labour and birth

These five episodes of care framed the construction of the discussion guide for phase two.

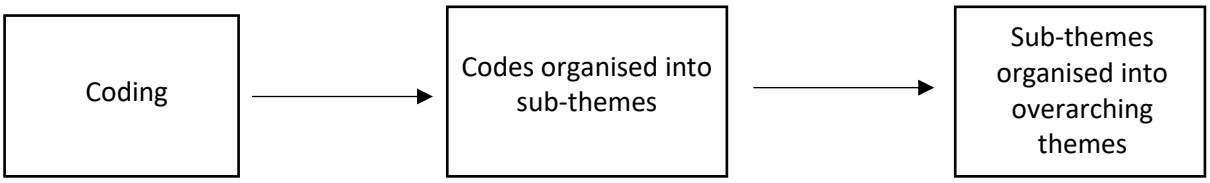

Figure 12: Analysis pathway

Figure 12 illustrates the analysis pathway from initial coding through to the interpreted themes. The first step in the analysis pathway was to analyse and code each of the transcribed interviews. All identified codes were collated in a 'codebook'. As the analysis of transcripts progressed, new codes were generated and included in the codebook. Once coding was completed, codes were organised into sub-themes relating to specific codes. Following the finalisation of the sub-themes, these were further analysed and organised into overarching themes; Table 5:6 presents the sub-themes and overarching themes following the analysis presented in section 6.2.

6.2 Outcomes of FGM survivors' one-to-one interviews

The FGM survivors' experiences of care are presented in the overarching themes. The participants' direct quotes have been used in this section *in verbatim* to preserve participant responses and 'voice'. (Corden and Sainsbury, 2006) explain that using direct quotes in qualitative research findings deepens understanding of the experiences of the participant whilst also giving the participant a voice. The list of FGM survivor participants can be found in Table 3:5 on page 160.

The following section presents the themes interpreted from the one-to-one interviews conducted with FGM survivors. Whilst the themes are presented here distinctly from

one another, each theme is related to one another which is presented in chapter seven.

6.2.1. Communication

Communication was a strong theme throughout the data and co-existed with other themes. There were mixed responses to the experience of the women participants at the beginning of their pregnancy. Some women felt that midwives did not listen or understand the concerns that the women expressed. Effective communication appeared to be a key factor in the initial stages of the maternity care episode; particularly listening to the needs of the women.

FGM survivors expressed positive experiences of communication when health care professionals asked questions about their FGM and the experiences of health related to this. However, communication was an overarching factor of the negative aspects of these experiences. The negative experiences suggested that the listening skills of some health care professionals were inadequate during their initial experiences. This can potentially lead to the planning of care that does not meet a person's needs. Listening to patients is a key component in their initial contact with health care professionals to understand the issues that are faced so that their needs can be met. Some typical examples of these responses included:

> *"to be honest with you, my midwife at the beginning was good, yeah she asked me about it but like I said before, the midwife I saw to be opened was ok so I wasn't worried"*
>
> *(FS04)*

"after my opening, I just didn't want to see anyone, so going to see a midwife eugh! I didn't want to. But she was good, really yeah […] I feel like she listened to me yeah"

(FS08)

"I saw a translator [link worker] at first and she was so lovely! I don't know why I saw her though because I can speak English. She asked me questions about my family and talked about my FGM. She knew a lot about it and I thought that she had got it! She made me feel comfortable and my worry went away after talking to her. I saw her again when I went to the clinic but saw a midwife in the clinic. I didn't feel so comfortable with the midwife though"

(FS18)

Despite the latter participant not seeing a health care professional for their initial appointment, their experience at the beginning of pregnancy was a positive one. The link worker was the same ethnic origin as the participant which may have contributed to the participant's comfort. However, the participant met with the link worker in a local community centre rather than at the main hospital clinic which suggests that environment may be a key factor in the woman's comfort. The woman was less at ease with the midwife in the hospital which further suggests that the environment may have been a key factor in the participant's comfort but may also suggest that the woman was less comfortable with a person of different ethnic origin. Whilst the link worker provided a familiarity to one woman and a sense of understanding, health care professionals' understanding of FGM was grounded in their education of FGM, which was outlined in chapter four, and as such may have introduced ethnocentrism into communication.

The lack of communication and understanding that some participants felt amongst the health care professionals resulted in a disparity of communication from the outset of the maternity care. This was further compounded when some of the women stated that they had pre-existing mental health concerns. Careful communication is crucial to understand these mental health concerns and careful planning is needed in conjunction with their maternity care. One participant explained how this affected the relationship with their midwife at the beginning of pregnancy:

> *"My community midwife is the only one I haven't had an entirely positive experience with […] she didn't really listen to what I am trying to express […] at the end she said I'll just write down that you have a phobia of childbirth […] I was really upset about this. I told her that it was not a true reflection of how I felt […] she hadn't really listened to me or heard me"*
>
> *(FS20)*

Furthermore, nonverbal communication is an important aspect of communicating but portraying some nonverbal communication can be accidental (Knapp, M. L. Hall, J. A. Horgan, 2013). Nevertheless, it is unknown whether midwives were aware that their expressions sent negative messages to the women but some women expressed feeling negativity in nonverbal communication from their midwife. An example of this included;

> *"when she [the midwife] asked me about circumcision I told her yes. I wish I hadn't because she changed after like she rushed to get me out. Why did she ask me if she didn't want to hear about it?"*
>
> *(FS10)*

In order for care planning to be effective, the communication between the women and the health care professional is intrinsic to the maternity experience; this includes any care plans that are assessed and planned during the labour and birth experience. However, during the labour and birth period of maternity care, plans of care may require minor to significant changes based upon the fluidity of needs of the woman and the baby during labour and birth. Nevertheless, wherever possible it is imperative to retain key points of the woman's birth plan in order that the woman maintains control of the birth experience. When pre-agreed birth plans require amendment, it is important that communication and information sharing is maintained. Yet, this was not always the case;

> *"When I was in labour, I didn't really want to have an epidural, but the doctors and midwives tried to talk me into it […] It felt like I wasn't really listened to but they [the doctors and midwives] were more bothered about getting me to have an epidural. Just before my baby was born, the doctor came in to cut my FGM open [...] I didn't really feel anything […] The first time I stood up it felt really weird […] I could feel stuff running out down there […] I haven't felt anything come out so fast before […] I felt like my insides were falling out"*
>
> *(FS15)*

In this woman's case, whilst her birth plan appears to be 'silent', there was also no information shared with her regarding the physiological changes following deinfibulation. Since the woman had no memory of experiencing normal vaginal flow of urine or menstrual blood flow it would have been pertinent for the midwife or doctor to discuss the expected physiological occurrences in relation to the woman's deinfibulation procedure during the labour and birth process. The woman was not aware that any vaginal loss would appear to be markedly increased following

deinfibulation due to a lack of information provided in the antenatal period. There was potential for the woman to experience trauma as a result of a lack of information provided regarding the normal expectations following the labour and birth episode.

Although birth planning was key in communication, this was also a central aspect of the FGM clinic and appeared to be one of the main reasons that women were referred to the clinic. However, the reasons for referral to the clinic were not always clear to the FGM survivors. This suggests that communication and information sharing did not meet the FGM survivors' needs. The following example supports this finding;

> *"the doctor there told me that I could have my baby naturally so didn't need to do anything else so not sure why I needed to go there"*
>
> *(FS02)*

A lack of communication was a theme amongst other responses from FGM survivors; this was reported throughout the maternity care episode. Typical examples of these include:

> *"it was all a bit of a blur. I don't remember that much of it and don't remember anyone talking about my FGM"*
>
> *(FS08)*

> *"I just hated every minute of being there. People talking about me and not telling me anything"*
>
> *(FS06)*

> *"when you've talked about what will happen to doctors before [antenatally] you think that when you are in having the baby they will already know what's going on. Every person that came in to see me I had to tell them again and again about it. Then they told me what they were doing, not ask me what I want to happen. I didn't have a choice"*
>
> *(FS03)*

Experiences of poor communication impacted on the women's relationships with health care professionals. One example of this was an FGM survivor who retold her experience during her first labour. She explained that the experience had such a profound impact on her that it affected her relationship with health care professionals during subsequent pregnancies.

> *"When I was in labour with my first child I remember them saying to me […] she tried to examine me and said, 'how have you got pregnant like this.' It really upset me […] the doctor came in and told the midwife to call her when the baby was coming and she would do a cut. They didn't even speak to me"*
>
> *(FS10)*

Discussing the legal implications of FGM is embedded into the clinical guidelines which inform the care for FGM survivors. The women described the effects of such discussions on their experiences of care. Overall, they felt that such discussions were persistent and had a detrimental effect on their experiences. This was evidenced in the data with typical examples including;

> *"I had help from my friend who came in with me when I had my baby but midwives didn't have time […] but talked*

to me more about the law! I wouldn't do that to anyone to make them suffer like I did"

(FS03)

"all they [midwives] care about is the law. I don't want to keep hearing about the law I want someone to help me with my baby! All they were bothered about was my FGM! What about women who don't have FGM?"

(FS19)

"I really wanted someone to help me but no one [members of staff] had time. One of them [midwives] came and talked about law and stuff to me and felt a bit bad because other people could hear. When they went [the midwife] I felt like everyone was looking at me. I felt like I'd something wrong"

(FS14)

Whilst there were examples of positive experiences of communication, the FGM survivors raised issues with communication. Negative communication was reported during all episodes of care; with verbal, nonverbal and cross-cultural communication all identified as negative experiences. The women participants who had negative experiences at the beginning of their pregnancies all described communication and cultural understanding as key factors to this experience.

6.2.2. Knowledge and education

The care experienced by the FGM survivors was dependent on the knowledge and education of the health care professionals. FGM survivors described health care professionals' reliance on categorising them into types of FGM to plan their maternity care.

"at the beginning, when I first saw the midwife, she asked me about FGM, then asked me what type I was. Type?? I have FGM! Isn't that enough to know? I've had babies before but she said I'd got to go to the clinic to be checked! Why though? I know I can have babies! It was a waste of time"

(FS09)

"the midwife asked me if I was cut and I asked why. She said she knew that women in my community were cut but how did she know about it? She doesn't know where I live or who is in my community and to be honest neither do I"

(FS14)

The latter was experience of a midwife assuming that the woman lived in a community with others from their own ethnic origin. In this case, the woman felt that the midwife's understanding was that all FGM survivors lived in practicing communities. However, it may have been pertinent to ask the woman whether she lived in a community with others from her country of origin and whether any were from areas that practiced FGM. Whilst this is an issue with communication, the knowledge and education of the midwife was lacking in terms of the personalisation of care. In contrast, health care professionals who ask the women open questions about themselves and FGM led to more positive experiences.

There was a repetition of women describing that they believed that they were being referred to social services with little understanding of the rationale for referral.

> *"when I was taken to the ward after having my baby I felt like I was left alone. A midwife came to see me at first but then I didn't see anyone for a long time. I asked for help two times but after that it was better to do things myself. They [midwives] told me that they would refer me to social services I think because of FGM. I felt like a criminal, like I would do this to my baby. They said if I didn't do this to my baby then someone else in my community might. She [the midwife] told me that she had to send a concern letter or something. I don't even know what that meant. I asked what the concern was but it was like she didn't know but she said it was the law. I honestly don't know anyone that would do this to their daughter, there probably is some that do but not where I live […] It's like everyone here thinks we all think the same"*
>
> *(FS15)*

The postnatal experience of this woman was echoed with the majority of the women interviewed and continued the antenatal theme of health care professionals' impressing the illegality of FGM to the women. All the women participants were referred to the safeguarding team via the referral form specific to the research site. However, the women expressed their concern regarding the title of the referral form and the midwives' perception that their babies were at risk of significant harm. Still, this concern is mirrored in the educational material that is specific to raising awareness and providing care to women who have experienced FGM as identified in the online training packages.

6.2.3. Service provision

The FGM survivor participants described several issues with service provision. Although there has been some improvement in geographical service provision, this remains an issue. Typical responses included;

"I wanted my FGM reversed when I came to UK, but most of this is done in London. It's so much money to go there that I don't have […] I saw a midwife in London to have my reversal […] she was nice, made me feel ok. But I ask her why I see a midwife, I not pregnant "

(FS04)

"London offers more help than anywhere else, but I didn't come to London so I had to travel there […] why is everything there?"

(FS18)

The majority of FGM specialist services are provided in the London area (FORWARD, 2019) due to recorded FGM prevalence being the highest in the greater London area. These women were required to access services in London due to a lack of availability in the local area at the time they were required.

All women who were identified as having experienced FGM during their lifetime were referred to the dedicated FGM clinic at the research site. Only one woman did not access the FGM clinic; the rest of the women described their experiences during pregnancy predominately surrounding their experience during this clinic. These experiences introduced doctors into their care experiences. There were mixed responses regarding the members of staff that the women encountered in the FGM clinic; typical responses included:

"…I was referred to the clinic where I saw a doctor. I felt like a criminal and a piece of meat. It all felt rushed like she wanted to get me out of the room […] she [the doctor] spent more time telling me about the law than about how my baby would be born. She [the doctor] made me feel

like I wasn't fit to be a mother. I was so upset that I phoned my [community] midwife and she told me to go back to the clinic to see the midwife there. When I did she had another look at me down there and said that I wouldn't need to be opened up for delivery. I felt like the doctor didn't really know about FGM. I think that they [health care professionals] should all know about this so no one else has to feel like I did…"

(FS19)

"when I was told that I was being referred to the FGM clinic I was really worried. You hear about it in the news don't you about people being arrested. But I honestly have to say that the midwife there was lovely. It was a good experience completely which I never expected. I thought that I would have to get on the bed so that she [the midwife] could have a look […] she showed me pictures that I could point at. The nicest thing was she believed me, she didn't ask if she could check or anything which I thought would happen"

(FS16)

It was noted that the specialist midwife had worked for a substantial number of years with FGM survivors so had the knowledge and experience that may have met the needs of these women. FGM survivors appear to have vastly different experiences and only through appreciation of the differences in experiences can empathy and understanding be achieved. It was acknowledged that the specialist midwife had gained this empathy and understanding following many years of working with, and learning from, women from different communities and cultures and therefore had the requisite tools and knowledge to provide culturally competent care. Conversely, the majority of women who received care from doctors expressed dissatisfaction with their care and felt that the doctors lacked knowledge and understanding of their needs. This was profound in the data as illustrated in the following example;

> *"when the doctor asked to look at me down there. When I asked why, she said to make sure it was safe for my baby. How could I refuse after that?"*
>
> *(FS14)*

Furthermore, experiences during any woman's labour and birth can have a significant effect which can be long-lasting (Sauls, 2002). Therefore, effective and comprehensive care planning during the antenatal period can have a significant effect on the care that women receive during the labour and birth element of care. Women who had experienced effective care planning, including birth planning, prior to their labour and birth experience described care that holistically met their needs. There was evidence in the data that when care was carefully planned, the service provided and the experiences were positive. A typical example of this included:

> *"I was most worried about was the pain. I had heard that I might have flashbacks because of the pain and the midwife talked about pain killers as soon as I was taken into a room. I wanted to have an epidural in case I had flashbacks and she got this sorted out for me straight away […] I needed stitches afterwards by he [the doctor] made sure that the pain killers were still working. I really can't fault anything about my labour at all"*
>
> *(FS07)*

Services provided for FGM survivors include deinfibulation services. At present, there is no standardisation of the provision of deinfibulation services which reflected in the responses from the FGM survivor participants. Four of the participants who had experienced a type III FGM had a deinfibulation procedure performed prior to marriage and pregnancy. All of these participants stated that they underwent the deinfibulation procedure prior to pregnancy so that they were able to have intercourse with their prospective husbands following marriage.

“it was just before I got married, I decided to have the reversal”

(FS18)

“I needed to have it done so I could have relation with my husband”

(FS08)

The experiences of services reported by the FGM survivors were mixed which depended on their situation, environment the knowledge of the health care professional who provided their care. Some typical responses of these mixed experiences include;

“first time I saw my midwife was really good. She was really nice and kind to me. She was really helpful when I told her about how my FGM affected me which I didn’t expect really”

(FS15)

“I live in a secret place away from my husband and his family so they don’t know about this baby. Finding out I was pregnant was really upsetting, I’m not gonna lie and I have to take tablets because I am down a lot. But the midwife came to me which was so good”

(FS05)

“on the whole, the treatment that I had when I had my reversal was good. All of the nurses were really good and the male nurse that I had was the best.”

(FS20)

The deinfibulation experience before pregnancy for FS20 was positive. The clinical deinfibulation procedure and experiences with medical staff who were experienced in the clinical procedure assisted in this woman's initial discomfort. However, women also described their experiences of deinfibulation services prior to pregnancy as negative.

> *"they were like not very caring there and I felt on show which we don't do back home. I don't even show my legs to anyone […] I was glad to go home and didn't see anyone after"*
>
> *(FS08)*

The deinfibulation experience for these women was overall a negative experience. They expressed that they felt that the environment was not welcoming which affected their experience from the outset. FS18 was not prompted to give any further details of her experience prior to pregnancy due to the effect on her during this element of the interview.

Service provision may also be affected by the number of staff allocated to a clinical area. As such, the allocation of members of staff in maternity services can have a profound impact on the experience of service provision for FGM survivors. There was evidence that poor staffing affected the maternity care experiences with several women describing feelings of abandonment; particularly in the immediate postnatal period. Typical examples of this included;

> *"I really wanted someone to help me but no one [members of staff] had time. One of them [midwives] came and talked about law and stuff to me and felt a bit*

bad because other people could hear. When they went [the midwife] I felt like everyone was looking at me. I felt like I'd something wrong"

(FS14)

"one of them [member of staff] was really rude to me when I asked for help. She told me I wasn't the only person on the ward and had to wait. I was glad to be told I could go home"

(FS01)

6.2.4. Mental health care and issues

Several FGM survivors discussed mental health concerns and how their experiences of care were affected by either service provision, communication and/or health care professionals' knowledge. As such, this theme transcended all other themes with evidence presented from the data in these themes.

This transcendence of themes was evident in one woman's description of her experience of accessing counselling services in London following her deinfibulation. It was the woman's view that the counsellor placed a strong emphasis on her religion which may suggest that the counsellor believed religion to be a factor in the woman's experience of FGM. The woman believed that the counsellor also assumed that her previous Islamic faith had an influence on her mental health issues.

"By the time I got to speak to her I was having flashbacks and couldn't sleep. The counsellor told me that I needed to learn how to masturbate. I had recently converted to

> *Christianity and she told me that I had to work to break free of my Muslim shackles because I was suffering from neurosis due to the restrictions of Islam and needed to explore my sexuality. I honestly found her attitude appalling. She didn't know me and didn't know whether I knew how to masturbate or not!"*
>
> *(FS20)*

In contrast to this woman's clinical experience, the counselling experience was negative. This suggests that the FGM survivor's perception was that the counsellor had little understanding of her mental health concerns but interpreted her issues from a religious oppression perspective. Whilst this was an issue with service provision and communication, there is also a strong link with knowledge and education.

There was evidence in the data that mental health care for FGM survivors is disjointed in maternity care. For instance, two participants described being referred back to their GP for assessment; this was despite the same participants having already been assessed by their GP and in receipt of treatment. Furthermore, neither participant was referred to the maternity mental health service despite this being provided under the same 'vulnerable women's service' as the FGM service.

This point marks the end of phase one. The next stage of analysis introduced the second group of participants, namely the health care professional focus group. The aim of this group was to provide a further layer of analysis by ratifying, refuting or challenging the findings from phase one. As such, the discussion guide for the health care professional focus group was developed from the themes interpreted from the FGM survivors' responses during the one-to-one interviews.

Table 5:6: Sub-themes and themes interpreted from the one-to-one interviews with FGM survivors

Sub-Theme	Theme
Good communication Poor communication Explanation Language barrier	Communication
Good health care professional (HCP) knowledge Poor HCP knowledge Assumption Culture Religion	Knowledge and education
Service provision Clinical procedures Experience of HCPs Choice	Service provision
Posttraumatic stress disorder Depression HCPs incorrectly interpreting issues Disjointed care	Mental Health care and issues

6.3 Development of discussion guide for phase two

The aim of the health care professionals' focus group is to review the findings from phase one of the analysis. Therefore, the discussion guide consists of questions that are marginally different to those included in discussion guide for FGM survivors.

Analysis of the FGM survivors' responses was an iterative process from the first to the final interview to ensure the capture of rich data and confirm data saturation. In parallel to this iterative process, the discussion guide for phase two was drafted to respond to some issues that arose from the FGM survivors' interviews. Therefore, the discussion guide was framed on the experiences of care during the natural progression of maternity services that the FGM survivors provided. However, it was vital that the themes interpreted from the data were also included in the discussion guide. The final discussion guide for the health care professionals' focus group consisted of five key areas for discussion (see Appendix VII) with each of these encompassing probing questions around the themes interpreted from the data at phase one.

6.4 Phase Two: Professionals' focus group

The second phase of analysis was to provide the collective voices analysis to the first stage of analysis. The intent was to present the findings to the focus group to ratify, refute and/or challenge the interpreted data from phase one. As such, there was not intent to generate sub-themes and overarching themes in the same manner as phase one. However, new data was collected which generated new sub-themes. Nevertheless, these sub-themes were relevant to the existing overarching themes interpreted from phase one and were incorporated into these.

In the case of this study, the collective voices consisted of health care professionals who had experience of the care of FGM survivors. There was also a voluntary sector worker who originated from the community where FGM is practiced but had not experienced FGM.

The full list of health care professional participants can be found in Table 4:5.

In the original construction of the silences framework, the collective voices are positioned following those who are perceived to be silent. Whilst that remains true of this study, these collective voices are positioned between one-to-one interviews with FGM survivors and a further discussion group of FGM survivors. The rationale for this was to enable the latter group to reflect on the data generated from the health care professional focus group. Whilst Janes et al. (2018) argues that this stage is only appropriate for analysis and not collecting data, there is opportunity to identify further silence amongst the health care professional collective voices which is a valuable insight into the care provided. Equally, as a phased model of analysis, which involves introducing a new participant group at this point, it is naïve to believe that further data will not be generated. Furthermore, modifying frameworks in this way can provide a deeper richness to the data and, in some cases, be more suitable for the analysis (Dixon-Woods, 2011; MacFarlane and O'Reilly-De Brún, 2012)

There were two aims that were relevant to health care professional participants in this study which were referred to during the focus group. These were incorporated into the findings from the FGM survivors' one-to-one interviews. The aims relevant to this focus group were:

- *Does health care professional knowledge of FGM have any impact on the care that FGM survivors receive in maternity care?*
- *Does language and communication affect the care that FGM survivors receive?*

Furthermore, the objectives relevant to the focus group were:

- *Explore the experience of UK maternity services of FGM survivors*
- *Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors*
- *Critically examine the education and guidance widely available to health care professionals on FGM*
- *Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally*
- *Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.*

6.5 Outcome of Health care professionals' focus group

The aim of the focus group of professionals was to provide a second phase of analysis of the data collected from the FGM survivor participants. Yet these collective voices also provided further data on health and social care professional opinions and interpretation of the FGM survivor views. The interpreted themes appeared to be ratified during this phase but some new information began to emerge. There appeared to be a lack of cultural understanding from all except for the member of the focus group who worked in the voluntary sector.

Furthermore, there appeared to be a universal belief amongst the health care professionals that all FGM survivors, or members of their community, will conform to the historical cultural philosophy of FGM and thus any female offspring are at risk of the practice. Nevertheless, it cannot be assumed that all FGM survivors and their families reject the practice therefore it is imperative that comprehensive education for health care professionals is available so that this differentiation can be identified and unnecessary referrals to social care are reduced.

The views from the health care professionals and volunteer sector worker also provided a further perspective on the initial findings. The views differed depending upon which sector that the individual practiced. One view from the volunteer sector identified that children are potentially at risk of FGM in the UK but protection of the children of women living with FGM is often complex.

> *"women understand that the practice is wrong. I remember a woman who I met with about 15 years ago who had arranged for her daughter to be cut […] The woman regretted having her daughter cut and went to the police to tell them what had happened […] it was not in the best interests of the child to be removed from the family home because they considered it as a one-off form of physical abuse. They also said that they did not consider it in the best interests of the child to remove the mother as they believed that the child had an otherwise loving environment. It makes me wonder how many times and how many children have slipped through the net*"
>
> *(HCP08)*

6.5.1. Pre-pregnancy care

There were four FGM survivors interviewed who experienced pre-pregnancy deinfibulation. One of the issues that these FGM survivors experienced was access to such services. Access to pre-pregnancy services for FGM survivors was discussed with the group.

> *"deinfibulation is quite specialist so they will be concentrated in areas like London […] I'm not sure of the need around here"*
>
> *(HCP06)*

"I don't think there's any services really that's specific to FGM survivors […] it's quite niche isn't it, so it wouldn't be a priority for the NHS budget I reckon"

(HCP07)

The discussion around pre-pregnancy raised some interesting points. Initially, the assumption was that pre-pregnancy care for FGM survivors would solely encompass deinfibulation services. However, one health care professional recognised that FGM survivors may need extra support with conception care. RCOG (2015) indicated that one of the long-term implications of type III FGM is infertility which may be due to impaired menstrual flow, impaired urine flow or both.

6.5.2. Mental health care

Mental health concerns were issues identified by a number of women. In section 6.2.4, one FGM survivor disclosed PTSD emerging following deinfibulation and the sub-standard counselling she later received. A number of other FGM survivors described varying degrees of depression during the one-to-one interviews. Therefore, mental health care of FGM survivors was discussed with the group.

"well, mental health assessment needs to be done by the GP so when women raise mental health concerns, guidelines tell us to refer them to their GP"

(HCP03)

"if we pick up mental health issues we would refer to the GP. Well, that's what our guidelines say anyway and I would follow that"

(HCP07)

This statement was unanimously agreed by the group; therefore this was explored further. The women who raised mental health concerns, including the woman with PTSD, had already received assessment and diagnosis prior to pregnancy and therefore did not require further assessment and diagnosis from their GP. When informing the health care professionals of this, they raised concerns regarding the lack of knowledge of mental health concerns that were related to FGM.

> *"it's difficult with FGM women because an FGM midwife isn't a mental health specialist and a mental health specialist midwife isn't an FGM midwife […] a mental health midwife will get the same FGM training as the rest of us and an FGM midwife will get the same mental health training as the rest of us"*
>
> *(HCP04)*

The health care professionals all raised their concerns regarding the lack of mental health care that was tailored for FGM survivors.

> *"I just wonder how much damage has been done to these women, especially in women with PTSD […] there needs to be more, I don't know, mental health support for FGM women"*
>
> *(HCP08)*

> *"but it might not be because of the FGM had it? It might be because of moving here and being isolated, or like the woman with PTSD, because of deinfibulation"*
>
> *(HCP02)*

> *"couldn't there be something joined like mental health and FGM? Like both specialist midwives doing training about it or something?"*
>
> *(HCP01)*

Although some FGM survivors disclosed mental health concerns as well as fear and anxiety at the beginning of pregnancy, others expressed feeling of excitement and joy and felt their pregnancy was a happy event. Yet the health care professionals believed that FGM survivors were particularly vulnerable and feared contacting the maternity services due to the potential of children's services involvement.

> *"I think that women don't want to say about their FGM at booking because of the referrals they know we will make. With all the hype in the news about FGM I think they [the women] are scared to talk to us about it. But really, all we want to do is make sure that they have the support they need, and their pregnancy and delivery are safe"*
>
> *(HCP02)*

6.5.3. Care planning and clinical guidance

Recommendations for care and care planning in clinical guidance appeared to be an overwhelmingly important aspect of providing care to FGM survivors. The midwives mentioned that the local guidelines stated that women who were identified as FGM survivors during the antenatal period were required to be referred to FGM services. However there was some misplaced knowledge that alluded to midwives believing that it was a legal requirement to refer women to specialist services. A discussion took place regarding the differences between policy and guidelines but it appeared that these were regarded as the same.

> *"to us, policies and guidelines are the same because we are judged on all of it. If we don't follow the guidelines like the policies then we know about it!"*
>
> *(HCP01)*

> *"Yes, they might be called guidelines but we don't have a choice whether we follow guidelines or not. If the guidelines say that the women should be referred then we refer the women. If we didn't refer a woman, then someone else would"*
>
> *(HCP06)*

It was noted that there was no differentiation between policy and guidelines from the perspective of the health care professionals. When exploring the reason for this, it was identified that during audit and case investigations, recommendations listed in guidelines were measured in the same way as standards within policy and were reported as such.

The illegality of FGM is featured in all guidance for the care of FGM survivors and discussions of the legal implications were a dominant feature of the FGM survivor's experiences in the immediate postnatal period. Some FGM survivors felt that the midwives placed the discussion around the legal implications of FGM ahead of parent education. The group were questioned on parent education provided in the postnatal area and whether the legal implications was an important part of this discussion. There was further evidence that regulation and performance indicators were important when providing care. Typical examples of the responses included:

> *"it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged"*
>
> *(HCP01)*

"trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so it's important they understand it"

(HCP09)

6.5.4. Service provision

Some of the women participants questioned the referral to specialist services and the nature of this. They were concerned that the paperwork at the research site which identified other professionals of their FGM had negative connotations due to the use of the word *concern* used in connection with the referral. They believed that the title of the document itself indicated that their child was at risk or that their child's safety was in doubt. A number of the women were unaware that this referral had been made. Adams (2014) stated that informed consent is required when any referral is made to any service and failure to seek such consent is unlawful and unethical unless the woman or any children would suffer as a result. Therefore, this was addressed with the health care professionals.

"I think they do all the safeguarding stuff in the clinic for the women and the ones that need type III opening is sorted there, as far as I know, that's it, but the safeguarding bit is important"

(HCP09)

"yeah, safeguarding is important for these women. OK, it might not be the woman herself who agrees with FGM, but what about her family or someone else? Children have slipped through the net before, not with FGM but with other things. If we haven't referred women to the clinic and something happens, who's to blame?"

(HCP02)

Some midwives believed that the safeguarding element of the care planning and provision was the most important element of care. Indeed, Creighton et al. (2015) emphasis that the safeguarding element of care provision is the most important when caring for FGM survivors. However, this notion was not shared with the FGM survivors.

The FGM survivors believed that safeguarding was unnecessary as they unanimously stated that they did not conform to the historic culture surrounding FGM. The women suggested that their midwives had made an assumption regarding their belief of FGM based on their cultural heritage and did not take account of their views. The women referred to the referral process and the document titles in their concerns. These concerns were referred to the group for their responses and interpretation to the views that the woman highlighted.

> *"Whether the woman likes it or not they have to refer them to FGM clinic and to the safeguarding team. I suppose it depends on safeguarding whether they refer them [the women] to social services. I don't remember anyone being referred to social services though"*
>
> *(HCP04)*

These responses appeared to indicate that referral to FGM services was mandatory. The health care professionals believed that safeguarding services were a particular feature of FGM services which may need careful discussion with FGM survivors regarding referral to such services. Negative communication was a consistent theme from the FGM survivors' interviews therefore the group were questioned regarding communication skills with FGM survivors. The responses indicated that communication with FGM survivors was complex due to their potential vulnerability and referral to the

FGM clinic or other vulnerable women services was important. Examples of such responses include the following;

> *"the vulnerable women midwives looks after women who are vulnerable, like mental health issues, teenage pregnancy, drug users and all things like that"*
>
> *(HCP06)*

> *"yes, doctors also provide care in the clinic, usually for women who need more complex care planning"*
>
> *HCP03)*

6.5.5. Knowledge and education

The health care professionals all stated that when providing care to FGM survivors, they were expected to also provide these women with health education and support. They were concerned that they did not have the expertise to provide mental health care to FGM survivors and further questioned whether training around FGM was adequate. The following quotes support this finding;

> *"well, there's that training, but there is also online training that we all should do. It's part of our mandatory training so everyone should have done it"*
>
> *(HCP07)*

> *"I mean the training isn't enough really, it doesn't tell us anything about culture or what we should or shouldn't do"*
>
> *(HCP03)*

"exactly, and more to the point, we haven't got a clue about the culture of this but we are supposed to be telling these women what is best for them and their baby […] it's worrying really when you think about it"

(HCP04)

The differences in culture between the FGM survivors and the health care professionals were explored. Whilst the majority of the focus group did not believe that culture had any impact on the interaction between the FGM survivors and health care professionals, there were some concerns raised.

"they [FGM survivors] probably think we're interfering in something we don't know about. It's a bit like going back to the old colonial times probably"

(HCP05)

"I don't think it's as strong as colonialism, but I do think there is a lack of understanding on our part"

(HCP07)

"I disagree, we are trying to get a culture that we know nothing about to agree to our culture […] if that isn't colonialism, I don't know what is!"

(HCP04)

Whilst colonialism was identified in the literature with reference to rejecting colonial ideology and maintaining cultural and traditional practices, this was also raised in the focus group in relation to knowledge. When discussing this point, the majority of the

group stated that there remained little knowledge of FGM which potentially resulted in difficulties when providing care to FGM survivors.

Another interesting comment by one health care professional was a differentiation between FGM survivors and women who had not experienced FGM. The latter group of women were described as 'normal'. This notion was explored further with the group.

> *"well it isn't normal is it? I mean to do that […] what is normal about it?"*
>
> *(HCP01)*

> *"but what IS normal? Can you point at one [genitalia] and say yeah, that's normal? What about women with tattoos, piercings and that? Are they normal 'cus I wouldn't do that?"*
>
> *(HCP02)*

> *"yes, we see FGM in notes and the woman becomes the FGM, it's not just her genitalia. That's something we need to move away from"*
>
> *(HCP05)*

6.5.6. Communication

Communication was a dominant theme that was interpreted from the FGM survivors' responses. In particular, the FGM survivors' explained that during labour and birth they experienced negative communication, poor information sharing and cultural

insensitivity. Therefore, the labour and birth episode of care was discussed with the group with particular emphasis on communication and information sharing with FGM survivors. Some of the responses around communication raised issues with consent. Examples of these responses include:

> *"hopefully, all women understand what is happening during labour because we shouldn't – and couldn't – do anything without her consent […] whether she has FGM or not. What if she didn't understand what was going on? She wouldn't be consenting to what we were doing then! That's a whole can of worms"*
>
> *(HCP03)*

> *"women who have deinfibulation need to understand what happens after […] we are changing their genitalia which changes the way things like passing urine is […] making sure women understand is important, actually THE most important"*
>
> *(HCP04)*

> *"well, doing things like that [deinfibulation] we have to consent them which means they understand the benefits and risks of it […] if they didn't say they consented to it then we couldn't do it"*
>
> *(HCP02)*

> *"yes but are those women saying they consent or are they taking your word for it that it's the best thing for them? You might be assuming they understand when they might not really"*
>
> *(HCP08)*

The discussion around consent was particularly interesting since good communication and knowledge is crucial to informed consent; especially with the comment from HCP08 who had no previous knowledge of the consent processes in maternity care. Whilst good communication and knowledge is the cornerstone to discussions around consent in the clinical environment, it is impossible to know whether informed consent has actually been gained without routine debriefs for all patients who have undergone procedures. The group was questioned regarding the potential for labour and birth debriefs.

> *"What about talking to women after they have delivered? Would that be a better option than creating a whole new service? The women are already there and wouldn't have to go back in to talk about it […] they might not be bothered to come back or might be too busy with their new baby"*
>
> *(HCP08)*

> *"well I just wouldn't have time to sit and talk about anyone's labour and delivery because when I'm on shift I have to cover more than just delivery suite […] I could be needed anywhere in the hospital"*
>
> *(HCP05)*

> *"yes, when I'm on delivery suite, I could be looking after a labouring woman and as soon as she has delivered I would have to go to another woman […] there isn't time to sit with people and go through it afterwards"*
>
> *(HCP09)*

An overwhelming majority of the FGM survivors described negative experiences of their postnatal care. One of the most frequent issues was a feeling of abandonment. The group was asked their opinion of postnatal care as an inpatient overall and whether this differed for FGM survivors. This generated a discussion around safety of women and babies but also included discussion on statutory regulation. This suggests that, to midwives, regulation and performance indicators are most important when providing care. Some typical responses included:

> *"it depends how busy delivery suite is as well […] if there are more women in labour than midwives, which happens a lot, then midwives have to be pulled from postnatal wards […] at the end of the day, our first priority is to make sure everyone is safe […] that goes for the midwives as well, we have to make sure that they are safe!"*
>
> *(HCP07)*

> *"yes! I don't want to lose my pin number because of the amount of women I have to look after on delivery suite!"*
>
> *(HCP01)*

The aim of this focus group was to analyse the findings that were drawn from the FGM survivors' interviews. However, new themes were drawn from the health care professionals. In parallel, these themes were compared to the findings from the literature to establish whether the findings ratified or refuted the evidence in the literature. There were specific *new* sub-themes that were interpreted and organised into the existing overarching themes that are presented in table 6:6.

Table 6:6 compares the themes drawn from the health care professionals' focus group with the themes drawn from the FGM survivors' interviews. In the table, the left column represents these new themes with the right column presenting the themes drawn from the FGM survivors which relate to each new theme. The health care professionals described their training of FGM as inadequate and lacked cultural context and competence. When posing the query whether the lack of knowledge led to their own vulnerabilities in delivering care to women who had experienced FGM, the majority were in agreement. Knowledge and education was a dominant theme amongst health care professionals which was discussed in relation to health care education, guidelines and knowledge of services available to FGM survivors. However, this theme was symbiotic to other themes drawn from the focus group findings such as the culture intrinsic to FGM, institutional culture and service provision.

Table 6:6 Themes ratified and interpreted from health care professionals focus group

Sub-themes from phase one	Sub-themes from phase two	Overarching themes
- Good communication - Poor communication - Explanation - Language barrier	- Providing complex information - Difficult conversations	Communication
- Good health care professional (HCP) knowledge - Poor HCP knowledge - Assumption - Culture - Religion	- Agency and labelling - Consent - Lack of knowledge and cultural knowledge - Care planning and clinical guidance	Knowledge and education
- Geographical service provision - Clinical procedures - Experience of HCPs - Choice	- Statutory regulation - Meeting performance indicators - Service commissioning and need - Care debriefing - Referral to other agencies - Staffing issues - Institutional culture - Care planning and clinical guidance	Service provision Statutory regulation added as part of this theme
- Posttraumatic stress disorder - Depression - HCPs incorrectly interpreting issues - Disjointed care	- Disjointed service provision - Lack of mental health training and understanding	Mental health care and issues

6.6 Development of discussion guide for phase three

The discussion guide for phase three was derived from the interpretation of the data collected during phase two (the focus group of health care professionals). Whilst phase two was a layer of analysis, new data was collected that needed further analysis and ratification. The health care professionals stated that they felt health care education did not adequately cover cultural care for FGM survivors. Furthermore, guideline recommendations were a key feature of the responses of the health care professionals in terms of service provision. Hence the discussion guide for the FGM survivor's group consisted of the new data around the sub-themes of statutory regulation and health care education.

6.7 Phase three: FGM survivors' focus group

This phase of the analysis encompassed women participants being invited back to review the results of analysis in phase two. However, this was also an opportunity for the women participants to reflect on the further data that was gathered from the focus group of collective professional and voluntary sector voices. There was very little uptake of the offer to return to review the analysis of the focus group, many women expressing their lack of time due to the demands of caring for a new baby. However, two of the women participants returned.

Phase three of the analysis did not provide any new data but ratified the themes from the previous two phases of analysis. Furthermore, phase three was an attempt to re-balance the power between FGM survivors and health care professionals by providing FGM survivors with an opportunity to reflect on the findings from the health care

professional focus group. This phase of analysis presented an opportunity for FGM survivors to review and respond to the views from the focus group of professionals.

Furthermore, the aims relevant to the focus group of health care professionals were:

- *Explore the experience of UK maternity services of FGM survivors*
- *Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors*
- *Critically examine the education and guidance widely available to health care professionals on FGM*
- *Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally*
- *Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.*

Equally, the objectives relevant to the FGM survivor group were:

- *Explore the experience of UK maternity services of FGM survivors*
- *Explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors*
- *Critically examine the education and guidance widely available to health care professionals on FGM*
- *Critically examine the terminology used with FGM survivors and whether there is potential for culturally informed terminology that can be used universally*
- *Explore how the silences framework can be used to articulate experiences of FGM survivors and health care professionals' knowledge and understanding of the care needs of FGM survivors.*

During the discussion, the FGM survivors acknowledged and confirmed that the health care professionals lacked cultural knowledge. This exposed the reality that health care professionals are expected to provide expert care and advice to FGM survivors without

fully understanding the practice itself. This was strongly evidenced in the data collected during this phase;

> *"when you look at these doctors, nurses, midwives and see them trying to explain what I could be feeling or going through […] they don't know; they don't know me, you, her, any other woman […] how can they understand?"*
>
> *(FS02)*

As a consequence of the health care professional's lack of knowledge, the FGM survivors felt that assumptions were made based on their cultural background. This observation by the FGM survivors strengthened the theme of cultural insensitivity but also supported the theme of health care professionals' vulnerabilities when providing care to FGM survivors. The health care professionals' vulnerabilities were further raised by the FGM survivors during discussion and viewed statutory regulation as a barrier to providing effective care. An example of this discussion includes;

> *"yeah, it sounds like they don't want to ask us these things or talk about law whatever but have to because of rules […] its stupid, why can't they decide?"*
>
> *(FS02)*

Mental health concerns were raised by some FGM survivors during the initial one-to-one interviews. Yet during discussion with the health care professionals there was concern regarding specialist knowledge of mental health care for FGM survivors; there was unanimous agreement that GP assessment was required. However, the FGM survivors felt that communication skills of health care professionals may exacerbate, or even cause, mental health issues. This was identified during FS20's one-to-one

interview where knowledge and assumption was a key issue and further ratified during the FGM survivor's focus group;

> *My sister was very happy when she went to see a midwife first time but very sad when she came back. I asked her what happened and she said they talk about social; will they take my baby? Why scare her like that? They don't know how she feels, they don't ask"*
>
> *(FS15)*

The FGM survivors felt that health care professionals lacked listening skills when caring for FGM survivors and unanimously agreed that health care professionals require education from a cultural competence perspective in order to understand the effects of living with FGM. This led to the FGM survivors suggesting that education should be developed with FGM survivors to ensure the inclusion of cultural sensitivity. When further explored, the FGM survivors felt that their input could improve clinical care by providing support and guidance on cultural competence. These suggestions included;

> *"who teaches these people about FGM? It doesn't seem like it's someone who knows about FGM or our culture"*
>
> *(FS15)*

> *"it's a shame really, to make these people have to care for something they know nothing about […] why don't they ask us? Why don't they get us involved?"*
>
> *(FS02)*

6.8 Outcome of phase three

This phase of analysis did not provide any new data but ratified the themes from the previous phases of analysis. Furthermore, this phase was an attempt to re-balance

the power between FGM survivors and health care professionals by providing FGM survivors an opportunity to reflect on the findings from the health care professional focus group. The opinion of the FGM survivors was that development of any education, policy, guidance or care provision should be designed in collaboration with FGM survivors to ensure that silences do not manifest in these. Table 7:6 presents the emerged themes thus far and the results of FGM survivor's discussion group. The first column represents the emerged themes from the health care professionals, whilst column two compares the FGM survivors' experiences with the health care professional's themes. The final column presents the FGM survivors opinions on the analysis and comparison of themes.

This marks the conclusion of thematic analysis for this stage of the silences framework. The next stage of analysis is a final researcher review of the findings overall as well as analysing the discourses in the literature and data to identify whether the findings ratify or refute the literature findings.

Table 7:6 Themes ratified by FGM survivor group

Sub-themes from phase one	Sub-themes from phase two	Overarching themes	Outcome of phase three
- Good communication - Poor communication - Explanation - Language barrier	- Providing complex information - Difficult conversations	Communication	The FGM survivors ratified the theme of communication and felt that this was symbiotic with knowledge and education.
- Good health care professional (HCP) knowledge - Poor HCP knowledge - Assumption - Culture - Religion	- Agency and labelling - Consent - Lack of knowledge and cultural knowledge - Culture of FGM	Knowledge and education	The FGM survivors ratified the theme of insufficient knowledge and education. It was suggested that FGM survivors should be key members in the development of knowledge and education for health care professionals.
- Geographical service provision - Clinical procedures - Experience of HCPs - Choice	- Statutory regulation - Meeting performance indicators - Service commissioning and need - Care debriefing - Referral to other agencies - Staffing issues - Institutional culture	Service provision and statutory regulation	The FGM survivor group ratified the theme of service provision. Furthermore, they interpreted statutory regulation and health care quality assurance as a barrier to health care professional's empowerment in service provision. As such, they also ratified the sub-theme of institutional culture.
- Posttraumatic stress disorder - Depression - HCPs incorrectly interpreting issues - Disjointed care	- Disjointed service provision - Lack of mental health training and understanding	Mental health care and issues	FGM survivors unanimously ratified this theme; specifically in relation to the sub-theme of lack of mental health training and understanding.

6.9 Chapter summary

This chapter has presented phases one to three of the analysis and the findings elicited from the data. Phase one uncovered that communication and cultural insensitivity were central themes of FGM survivors' experiences of maternity care, whilst phase two exposed a lack of knowledge and education around cultural aspects of FGM. However, phase two also revealed institutional cultural issues in maternity services which were associated with statutory and service regulation. Whilst phase three did not uncover any new information, it did ratify the findings from the preceding two phases of analysis.

The following chapter presents a final researcher review of the collected data to analyse and interpret silences.

CHAPTER SEVEN: VOICING SILENCES (STAGE THREE) (CONTINUED)

PHASE FOUR: FINAL RESEARCHER REVIEW

7.0 Introduction

This phase consisted of a final review by the researcher. Chapter four uncovered that power, vulnerability and agency appeared dominant in discourses in the existing literature. Chapter six presented the overarching themes that were interpreted from the experiences and provision of maternity care for FGM survivors. This chapter is orientated to interpreting the silences in the data by applying Foucault's theory of power in relation to the experience and provision of maternity care. The silences heard are presented in section 7.7 with a diagram (Figure 13) to illustrate their relationship with the overarching themes interpreted in chapter six.

7.1. Summary of the interpreted themes

The overarching themes that were interpreted from the data appeared to be symbiotic and suggest that the care provided to FGM survivors may not be effective in meeting their needs from a cultural perspective. This was interpreted from the theme of service provision with the themes of knowledge and education, communication and understanding of mental health care needs appearing to be interdependent with this theme. The critical review of literature in chapter four suggested a link with maternity service provision and power; particularly with reference to Evans et al's (2019) finding that clinicians attempted to exert power in clinical situations with FGM survivors. However, the presence of power in a relationship suggests that vulnerability also exists in the same relationship which may lead to uncovering silence in that relationship. In

the context of this study, that relationship is between the FGM survivors (the service users) and the health care professionals (the service providers). As such, words used during data collection, organisational norms of maternity services and the dominant discourses around providing and experiencing care were extracted from the interpreted themes to interpret (or 'hear') silences across the data.

7.2. Analysing discourses

Mills (2004) posited that discourse theory according to Foucault has been particularly useful in theorising power, which appeared to be a dominant theme in the literature. Whilst a Foucauldian Discourse Analysis was not the main method for interpreting the overarching themes for this study, Foucault's (1977) theory for interpreting power was applied to the data in the interpreted themes to interpret the root of silences. When applying Foucault's (1977) interpretation of governmentality and panopticism to the data, it was found that power, vulnerability and agency interpreted from the critical review of literature, transcended each of the interpreted themes. This was an important process in interpretation of silences across the data.

7.3 Governmentality

When Foucault described governmentality, it was to describe the individual's willingness to participate in their own government. In other words, individuals in society are active participants in governing themselves. According to Foucault, the state exerts control over the population by disseminating power so that the individual governs oneself. This is achieved through categorisation in terms of household, economic status, education and race. This draws significant parallels to the FGM dataset where

FGM survivors submit themselves for categorisation for prevalence rates based on their country of origin and type of FGM.

Yet Foucault differentiated between political rationalities, which were termed 'genealogy of state' and ethical questions which were termed 'genealogy of the subject' (Lemke, 2000). Petersen and Bunton (1997) described Foucault's position on the emergence of two axis in healthcare; (i) bio-power which described working with individuals and (ii) bio-politics of population which was working with the populous. In other words, the human body is subjected to observation and regulation through objectification, particularly through health education and health promotion whereby the diffusion of power to the population through knowledge ensures that the individual self-governs their own health. As such, the aim of this power is to construct docility whereby bodies can be observed, measured, transformed and enhanced (Petersen and Bunton, 1997). Foucault (1982) explained that the three pronged approach to the panopticon (or social prison) can be observed in institutions such as prisons, schools and hospitals. But from the perspective of this study, this can also be seen in the maternity care of FGM survivors.

7.4 Maternity service provision

Understanding the organisational norms of maternity services was an important step in the analysis which aimed to determine whether power existed in the service itself. Therefore, at this stage of analysis, maternity service provision has been compared with Foucault's (1977) interpretation of panopticism. An eighteenth century philosopher, Jeremy Bentham, created the concept of a panopticon, or prison, in which

minimal surveillance was required. The concept was to create a prison that enabled one guard to maintain surveillance over all prisoners (Laval, 2012). This was achieved by constructing a round prison with the guard tower at the centre; whilst the guard was able to see the prisoners at any time, the prisoners were never able to see, or know, when they were being observed. As such, it was Bentham's theory that the prisoners would constantly exhibit 'model behaviour' since the acknowledgement of 'good behaviour' resulted in rewards such as shorter sentences. Foucault took this concept further and theorised the social panopticon or modern social prison where all members of society self-govern through the diffusion of power. Foucault described the 'three-pronged approach' to control (Foucault, 1977) which, from the perspective of this study, is applicable to maternity care; FGM survivors accessing maternity care as well as health care professionals' practices.

Hence, this phase of analysis proposes that the maternity care system in England and Wales can be directly compared with Foucault's theory of the social panopticon. Maternity care is underpinned by surveillance of clinical guidelines through audit and service evaluation, and subsequently, higher authorities such as the CQC. As such, each FGM survivor who enters into this care is constantly under examination by midwives, obstetricians and other professionals within the maternity care sphere who strive to attain as close to a 'normal' birth as possible. This is achieved by: (i) surveillance, (ii) normalisation and (iii) categorisation.

Self-government is an important Foucauldian concept which appears to have been internalised within maternity care and was reflected in the theme of service provision

and statutory regulation. There seems to be constant pressure of health care professionals to be mindful of performance indicators and ratings through CQC inspections; such inspections of services are based on five 'key questions' or performance indicators:

1. Are they safe?
2. Are they effective?
3. Are they caring?
4. Are they responsive to people's needs?
5. Are they well-led?

(CQC, 2018b)

Data collected from the health care professionals strongly supported the notion of this in the theme of service provision and statutory regulation;

> *"I think that it is safest for all that they make the referral. I don't really discuss the referral with the women anyway because what can we do? Isn't it the law that we have to make the referral?"*
>
> *(HCP04)*

> *Q: "Can you tell me more about the safety for all? What drives this safety and who determines what is safe?"*

> *"if it's in the guidelines to make the referral, then that's what we have to do. It's up to the woman or not whether she goes, but thinking about it, if it's something to do with safeguarding and she doesn't go to the clinic, I'm thinking that safeguarding are informed anyway"*
>
> *(HCP07)*

Q: "So is it safeguarding or the guidelines that determines this safety, or both?"

"I suppose both really. In investigations, I know notes are scrutinised against guidelines, I've seen it […] if someone hasn't followed them to the letter then they are hauled over the coals! But these investigations show whether we have given safe care or not, you know, the five questions and that."

(HCP07)

Hence, whilst maternity care is guided by RCOG, NICE, the WHO and so on in clinical guidance, overall surveillance and examination of the maternity services is measured by CQC. As such, health care professionals appear to internalise the need to demonstrate maternity care provision that maintains good scores within CQC performance indicators.

During maternity care, FGM survivors are under continual surveillance from expert decision makers such as health care professionals. Hence, it appears that the health care professional is situated in the 'watchtower' of the panopticon as described by Foucault (1977) with the FGM survivors aware that this surveillance is continuous. Antenatal care surveillance is documented, data is then generated and archived and as a result, strengthens the power-knowledge relationship. Maternity care notes are then regularly scrutinised by maternity services through audit and evaluation to measure the overall care outcomes but, as in the case of the panoptic prisoner, FGM survivors do not know when exactly such scrutiny will be performed. In parallel, information regularly submitted to NHS Digital's dataset of nationwide FGM prevalence

is collated and scrutinised in the same way. Reports are then regularly compiled by experts who are unseen and/or unheard by the FGM survivors.

Yet, the health care professionals are also situated as ‘prisoners’ of the panopticon of maternity care. Higher authorities such as CQC, NMC (in the case of midwives) and GMC (in the case of doctors) are constantly reviewing care provision and competence of health care professionals by collating data and compiling reports on performance and quality of care. As such, these higher authorities are situated in the watchtower with the health care professionals situated on the fringe (as ‘inmates’ of the panopticon). Furthermore, the environmental construction of maternity service provision can be compared to the panoptic structure. On initial access to maternity services, FGM survivors are assessed in a consulting room within a GP surgery. The midwife is positioned at a desk with a computer screen which can access information about the FGM survivor. The midwife collects further data about the FGM survivor but the FGM survivor in unable to see this information. This is then stored, collated and grouped into a central care plan that is available to members of the FGM survivor’s care team. Every time the FGM survivor accesses care during the maternity care episode, the information in the care plan is amended, regrouped, re-collated and further analysed. However, this information is not seen by the FGM survivor themselves. As such, the FGM survivor becomes the object of data collection but not an active subject in principle decision-making. This creates a power imbalance whereby the health care professional is powerful in questioning the FGM survivor and the FGM survivor is less powerful by submitting to answering such questions. Hence, the health care professional and the FGM survivor may have unintentionally

internalised the concept of the panopticon by becoming the observer and the observed. This was supported in the theme of communication in the data;

> *"didn't mind the questions at first but there was some I didn't know about like my family because they don't live here. When she [the midwife] asked me about being circumcised she said she had to fill a form out for a clinic which was alright"*
>
> *(FS03)*

> *"specialist midwives ask these women specific questions about their FGM […] sensitive communication is key with this group of women because they are particularly vulnerable […] they are used to talking to women who need extra support like that"*
>
> *(HCP01)*

Yet Foucault (1982) described a *double bind* which simultaneously exercises individualisation and totalisation. This is an important feature in maternity care for FGM survivors which stems from clinical guidance and recommendations. For instance, FGM survivors are decontextualized, assessed and examined which positions the FGM survivor as an objectivised subject in terms of risk assessment and care planning. Yet, the care planning itself is based on a generalised care pathway (see Appendix XIII) which aims to treat FGM survivors equally. Hence the FGM survivor is both individualised and totalised.

Risk assessments and care planning are collated and analysed to establish the appropriate care for the FGM survivor. This process constitutes a data collection exercise in which the FGM survivor is heavily scrutinised. This then creates an archive

of knowledge and documentation about FGM survivors, the impact of their pregnancies, the impact of labour and birth and so on. As such, this places the FGM survivor as a central subject within this surveillance and data collection system. This is a prime example of Foucault's description of the power/knowledge relationship whereby;

> *"these practices of surveillance, elicitation and documentation constrain behaviour precisely by making it more thoroughly knowable and known. These new forms of knowledge also presuppose new kinds of constraint, which make people's actions visible and constrain them to speak. It is in this sense that Foucault spoke of 'power/knowledge'."*
>
> (Rouse, 2005b)

Within this power network, health care professionals take on the role of expert and steer FGM survivors through the maternity service in directions of particular decisions regarding aspects of care such as referrals to FGM clinics and decisions of place and mode of birth. This is due to health care professionals having subjected themselves to scrutiny and demands of the higher authorities rather than FGM survivors' preferences of care. This was reinforced in the data;

> *"any kind of referrals made are dictated by whatever guidelines say. If we start ignoring the guidelines then what's the point of having them? Guidelines are based on evidence of what the best care is. So we follow these because it has been proved that this is the best thing to do"*
>
> *(HCP09)*

> *"the guidelines say that women should be referred to an FGM clinic. I don't know what they do in these clinics, as*

far as I know they do all the care planning there. Obviously I look at the woman's notes after"

(HCP01)

As Foucault (1977) described the reconstruction of the justice system in the eighteenth century, so too can the health and social sciences construction of the FGM survivor be described. They are viewed as dependent on maternity care by becoming reliant on them to meet their needs and navigate them through the care planning system. As such, they submit themselves to scrutiny and control. Since FGM is viewed outside of western society norm, FGM survivors are 'pathologised' and scrutinised and viewed as 'deviant' to bodily norms. This was strongly supported in the data;

Would these women be treated differently to normal women?"

(HCP01)

"I think what you're saying is the woman's normal, it's the FGM that isn't?"

(HCP04)

"yes, we see FGM in notes and the woman becomes the FGM, it's not just her genitalia."

(HCP05)

Hence it is suggested that there is a connection between health and bodily deviancy and FGM which has been understood by the reference to FGM survivors having

‘abnormal bodies’ that have been ‘mutilated’ (Evans et al., 2019). Although contemporary UK society is underpinned by the ideology of individualism, equality and freedom, maternity services appear to scrutinise and alienate FGM survivors for having experienced a cultural practice that is outside of western society’s cultural norm. In parallel, CQC (2018a) posited that women expressed their desire for *personalised* care, but this does not necessarily equate to individualised care; individualised care is measured, quantified and categorised, whereas personalised care is based on the needs, strengths and weaknesses of each woman.

Whilst there is some acknowledgement that FGM survivors may not have chosen FGM, this is confounded by the pathologisation and scrutiny of FGM survivors’ bodies. A dominant group’s ideology have always been endorsed as the norm (Noelle-Neumann, 1993b) with those outside this ideology portrayed as deviant and hence not heard. Dominant discourses exercise privilege to the versions of reality which legitimise existing power (Willig, 2013). As a result, it is suggested that FGM survivors accept such scrutiny and examination whilst internalising that their body is ‘mutilated’.

7.5 Discourses and experiences in maternity care

Health care professionals within maternity services are tasked to provide care during women’s pregnancies. In turn, women become the responsibility of the various health care professionals, such as midwives, obstetricians and other doctors such as general practitioners, anaesthetists and so on. These health care professionals have, over the years, developed knowledge and discourses on the care of women in pregnancy to explain pregnancy impacts on women, health impacts of pregnancy and pregnancy

outcomes and so forth. These discourses have been created through categorising women based on the types of impact; for instance whether a woman is considered to have a high risk pregnancy or low risk pregnancy and any other risk in between. Furthermore, modes of birth are categorised in the same way; for example, vaginal birth without intervention is categorised as 'normal birth' and any other birth is considered as high risk. Since high risk birth may increase the morbidity of women, the aim is to facilitate and promote normal birth for all women (Prosser, Barnett and Miller, 2018).

Although discourses are constructed around physiological care during the perinatal period, they are also constructed around psychological and emotional impacts. Whilst women may be categorised as low risk physiologically, they may be higher risk psychologically and/or emotionally. However women do not categorise themselves, maternity services apply such categories based on the need for health care professionals to apply specific care pathways for each woman. Discourse is strengthened within this categorisation by the words used by health care professionals. Such words and contexts distinguishes between women who are categorised as 'normal' and those who do not fit into the normal category as high risk.

7.6 Positions and subjectivities

In the discourse of maternity care, there are several types of people spoken about. From each subject position, there are ways of seeing, talking and acting associated with these positions which individuals may accept, challenge or reject (Willig, 2013). Many of these subject positions can be found in section six of RCOG (2015) guidance

on the principles of FGM management. This section is presented here to illustrate these subject positions which appear in bold for clarity;

> *"All acute trusts/health boards should have a **designated consultant** and **midwife** responsible for the care of **women with FGM**.*
>
> *All **gynaecologists**, **obstetricians** and **midwives** should receive mandatory training on FGM and its management, including the technique of de-infibulation. They should complete the programme of FGM e-modules developed by Health Education England.*
>
> *Specialist multidisciplinary FGM services should be led by a **consultant obstetrician** and/or **gynaecologist** and be accessible through self-referral. These services should offer: information and advice about FGM; child safeguarding risk assessment; gynaecological assessment; de-infibulation; and access to other services.*
>
> ***Health professionals** should ensure that, in consultations with **women affected by FGM**, the consultation and examination environment is safe and private, their approach is sensitive and non-judgemental and **professional interpreters** are used where necessary. **Family members** should not be used as interpreters."*
>
> (RCOG, 2015)

Within this text, there is evidence of subject positions of 'consultant', 'obstetrician', 'midwife', 'women with FGM' and 'family members'. Therefore, the discourse of maternity care makes spaces available for subject positions for each of these to inhabit, the consequences of inhabiting these positions and the relationship between positions (Willig, 2013).

The subject positions of consultant, obstetrician, gynaecologist and midwife in relation to specialist services exist in relation to women with FGM. In parallel, if there were no FGM survivors, then the FGM service would not exist. In other words, the subject

positions of consultant, obstetrician, gynaecologist and midwife in the specialist service rely on FGM survivors for their existence.

When the data was examined, there was evidence of these subject positions in relation to FGM survivors. However, in the discourse of maternity care planning there are other positions that are deemed to be superior;

> *"I was supported and referred to the consultant midwife who talked through the elective caesarean with me or a natural birth and I decided to go down the elective caesarean route although the doctors were against it"*
>
> *(FS20)*

> *"in my Trust, all these women would be referred to the vulnerable women midwives"*
>
> *(HCP09)*

It is noted that amongst these individuals, there are 'other' midwives whose roles have deemed them to be superior. This suggests that in these positions there are superior ways of being and seeing which may further legitimise their need to assume power in a relationship. However, for the purpose of this analysis, positions in discourse apply to all health care professionals (regardless of their role) and FGM survivors and the possibilities for speech that are acceptable or not acceptable.

7.6.1 Health care professionals

The discourse of antenatal care constructs the identity of carer which is a position available to midwives and obstetricians in that they assume responsibility for the FGM

survivor's, and their baby's, health during pregnancy. However, in the discourse of risk assessment during pregnancy, new identities are constructed that are available to the same individuals; these being assessor and manager. It can be argued that one identity may conflict with the other which is dependent on the individual's resistance. However, resistance is problematic since health care professionals' practices are regulated in statute. When speaking from the position of assessor, health care professionals are speaking within the realms of truth and knowledge from the perspective of western society's understanding of FGM which is grounded in second-wave white feminism and unreliable research findings. Yet within the discourse of antenatal care for FGM survivors is the discourse of accountability.

Since health care professionals are accountable to their respective regulatory bodies, it is suggested that their position of carer is seldom taken. Equally, the position of assessor and manager is fixed in statute via the FGM Act (HM Government, 2003). Deviation from this subject position may result in expulsion from respective regulatory registers. As a consequence, it is suggested that the health care professionals' subject positioning itself is under surveillance and observation from the watchtower of the panopticon and the reason why the position of carer is seldom taken.

Nevertheless, if the health care professional resists the position of assessor and manager and takes the position of carer, they are challenging the discourse of FGM, and maternity, management and contesting the mechanisms of the maternity care panopticon. But from this position, health care professionals fail to adhere to the rules and as such are disciplined, vilified and are required to undergo supervision to ensure,

in future, they conform to the governmentality of FGM services and panopticon of maternity services. Nevertheless, these positions have exposed silences in the discourses which is discussed further in section 7.7.

7.6.2 FGM survivors

In order to receive maternity care, FGM survivors have no alternative but to submit themselves to the perpetual surveillance of the panopticon of maternity services. However, they have three position from which to speak; victim, rebel and teacher.

During the discourse of risk assessment, the FGM survivor may take either position of victim or rebel. Whilst the position of victim is created in literature, the FGM survivor may internalise and verify this position. In this position, FGM survivors accept the governmentality of the maternity care panopticon and conform to the disciplinary power within the discourse of risk assessment. However, in the discourse of cultural care, FGM survivors may take the position of rebel; this is so positioned because cultural sensitivity is silent within the discourse of maternity care for FGM survivors. Both of these positions were strongly evidenced in the data;

> *"in my country we don't go around showing each other our bodies, especially 'down there' but I had to do that […] it was a horrible experience but they didn't seem to notice that"*
>
> *(FS18)*

> *"doctor wanted to have a look down there but, no. Like I said, I have babies before. She [doctor] was a bit rude about it […] why did she need to see? I told her I've had babies already with no problem!"*
>
> *(FS09)*

The position of rebel for this FGM survivor invoked a negative reaction from the doctor since she would not conform to the governmentality of the panopticon of maternity care. Yet these positions exposed silences within the discourses which are discussed further in section 7.7.

The third position available to the FGM survivor emerged during phase three of the analysis. This position bridges a gap between the position of victim and rebel in the discourses. FGM survivors have the position of teacher available in maternity and cultural care discourses. However, this position is not intended to challenge or repress the maternity care panopticon but to create the possibilities of new subject positions from where FGM survivors may challenge their care in maternity services. In turn, these new subject positions may challenge the knowledge and truth within the panopticon and discourses which, as a consequence, may improve the cultural sensitivity in maternity care for FGM survivors.

There were several dominant discourses that were extracted from the entire dataset which were embedded in the overarching theme of service provision but were interdependent with each of the other themes. The dominant discourses interpreted from the data were (i) antenatal care, (ii) risk assessment, (iii) accountability and, (iv) cultural care. Figure 13 illustrates the dominant discourses that were interpreted across

the dataset and the relationship with the overarching themes that were interpreted during thematic analysis.

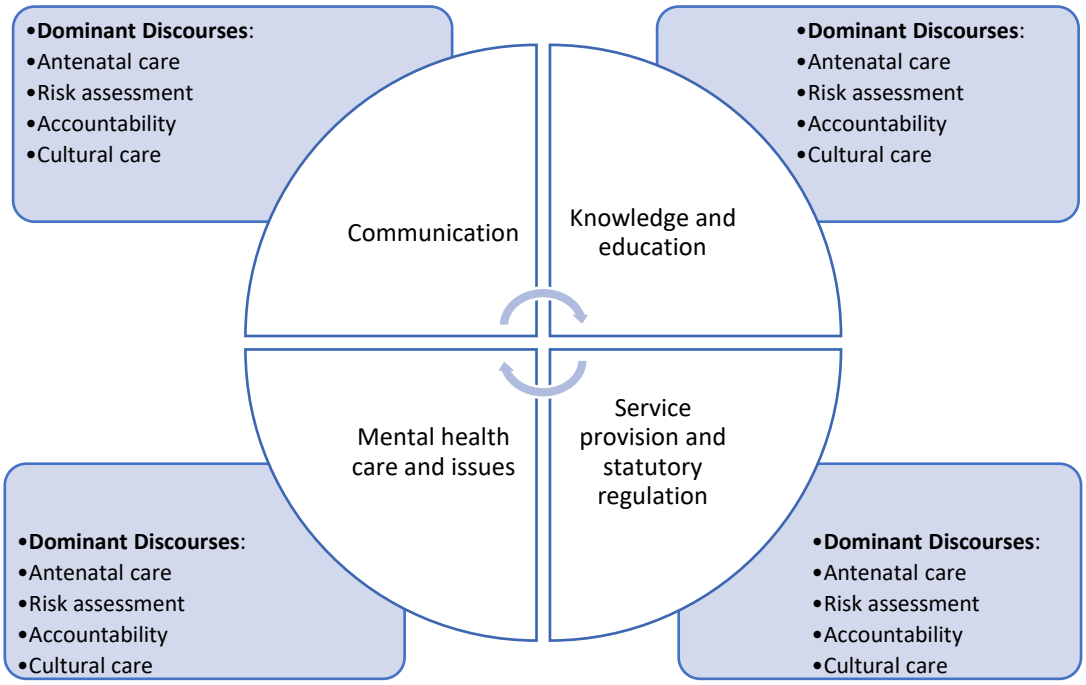

Figure 13: The relationship between the overarching themes and dominant discourses

7.7 Silences heard

Following the interpretation of dominant discourses across the data, silences were interpreted and exposed in both the FGM survivors and health care professionals which were co-dependent and internalised by both groups; the silences and their relationship with the themes are illustrated in Figure 14. The health care professional's position of carer (in terms of culturally sensitive care) appears to have been silenced in the discourses due to the governmentality within the panopticon of maternity care. Yet the health care professionals believed that their position of assessor *was* a position of carer due to their belief that the risk assessments were a necessary aspect of

reducing the risk of adverse outcomes of pregnancy[26]. But the position of assessor included assessing the risk of whether the FGM survivor supported the practice which, may result in risk to their unborn (or any other female children in their care or extended community) of FGM. This risk assessment is embedded in statute as well as clinical guidelines. The quality of clinical care is then measured through clinical audit which ascertains health care professional's compliance to recommendations in such guidelines. Since the legal guidance is embedded in clinical guidance, the performance of health care professionals providing legal advice to FGM survivors on the practice is also measured.

Furthermore, the outcomes of these clinical audits provide an indicator to authorities, who regulate and monitor clinical performance, of whether health care professionals are compliant in providing legal advice to FGM survivors. Yet it can be argued that legal discussions are not *clinical* guidance and as such should not be included in these guidelines. But the consequence of embedding these legal recommendations in clinical guidance is that health care professional's *carer* position in culturally responsive care is silenced by such regulatory authorities due to the requirement to meet performance targets. Nevertheless, there are further reasons why this aspect of the health care professional's position of carer is silenced which also relates to surveillance.

[26] Adverse outcomes of pregnancy may include preterm labour and birth, hypertension, pre-eclampsia and eclampsia, as well as assisted birth (using instruments such as Ventouse suction or forceps) and surgical birth (caesarean section).

WHO (1995) introduced the classification of 'types' of FGM based on the amount of tissue removed from the genitalia. But to determine a 'type' of FGM, genital examination is required. Since one of the aims of maternity care is to facilitate a vaginal birth, health care professionals examine FGM survivor's genitalia to determine the type of FGM and whether vaginal birth is possible without intervention such as deinfibulation procedures. In the discourse of antenatal risk, the health care professional again assumed the position of assessor. However, FGM survivors may originate from cultures where exposure of extremities such as arms and legs is outside of their norm (Huda, 2019). As a consequence, these genital examinations were deemed culturally insensitive by the FGM survivors. Yet to comply with clinical guidance, which is subsequently audited to measure the quality of care against performance indicators, health care professionals consider these examinations as necessary to determine the 'type' of FGM that the woman has experienced. So while the health care professional *should* have access to the position of carer in culturally responsive care in the discourse of antenatal care, this is silenced due to the health care professional's internalisation of the assessor position with the demand to obey the clinical guidelines. Hence it is suggested that the health care professionals' position of culturally responsive carer is silenced in the discourses by the requirement to comply with clinical guidance and meet performance indicators. However, this silence uncovered a silence amongst the FGM survivors.

The silence that emerged from the FGM survivors was synonymous with the health care professional's silence, as well as their position of assessor in the discourses. Whilst FGM survivors were viewed as victims, and the position of victim was available for FGM survivors from which to speak, their position of rebel was silenced in the

discourses due to the health care professional's position of assessor. But this led to the silence of the FGM survivor's cultural norms in the discourse of antenatal risk assessment. So while the position of victim was available to the FGM survivors in the discourse of antenatal care, this led to silence in discourse of cultural care where the FGM survivor spoke from the position of victim and the health care professional spoke from the position of assessor. This was strongly evidenced in the data;

> *"then the doctor asked to look at me down there. When I asked why, she said to make sure it was safe for my baby. How could I refuse after that?"*
>
> *(FS14)*

> *"I was referred to the clinic where I saw a doctor. I felt like a criminal and a piece of meat. The doctor looked at me down there and said that I would need to be opened to have my baby"*
>
> *(FS19)*

As such, while the health care professionals believed that the FGM survivors were vulnerable, it suggests that vulnerability was cultivated by the health care professional's position in the discourses and the silences of the carer position in the discourses and of the FGM survivor's cultural care.

This chapter has presented the interpreted silences around FGM which are focused around power, vulnerability and agency in the dominant discourses and appear to exist in the maternity service provision for FGM survivors. Figure 14 presents an illustration of the relationship between the interpreted themes from chapter six, the dominant discourses interpreted in this chapter and the proposed silences that have been heard following this analysis.

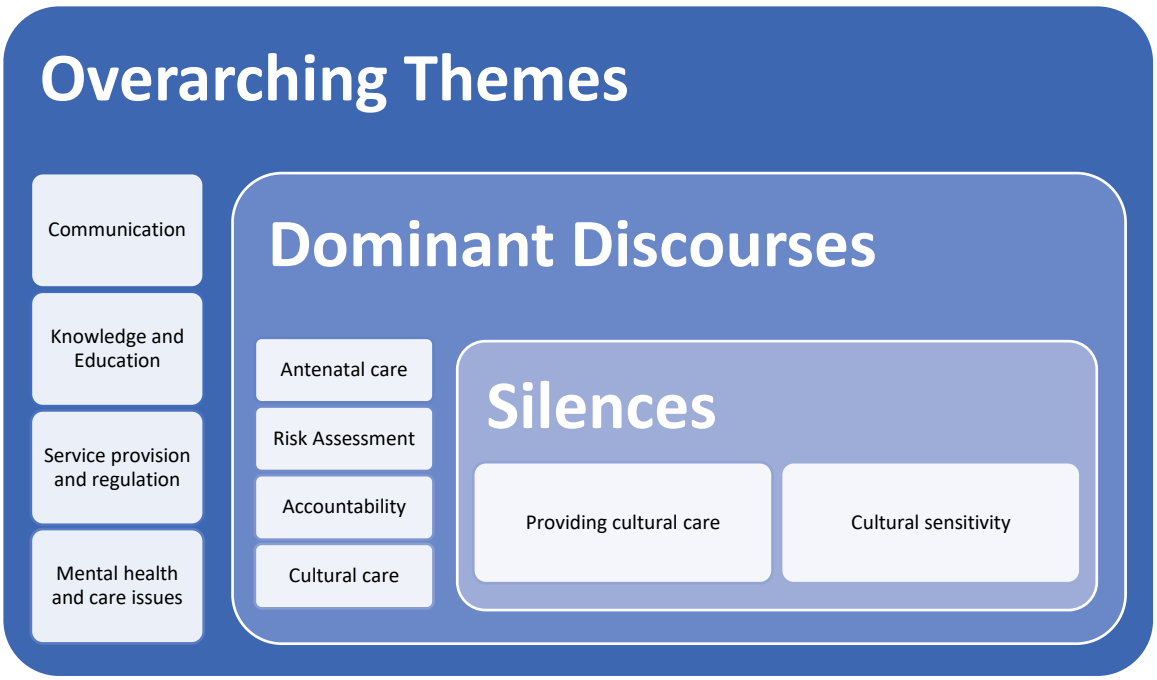

Figure 14: Relationship between overarching themes, dominant discourses and silences

7.8. Chapter summary

This chapter has presented an analysis of the discourses of maternity care of FGM survivors. The maternity services have been regarded as a panoptic structure of regulatory power which exposed that health care professionals are silenced in the discourses due to statutory regulation and adhering to performance indicators. In fact, using the term *care* in relation to FGM survivor's maternity care is deceptive since continual surveillance, observation and collation of data on FGM survivors prevents health care professionals from truly *providing* culturally responsive care. In turn, FGM survivors are denied cultural sensitivity since they can only adopt the positions of victim or rebel in these discourses. Yet by rejecting cultural insensitivity and thus adopting the position of rebel, FGM survivors are assumed to support the practice and are vilified as perpetrators because they do not conform to the perpetual surveillance and

examinations. As a result, when an FGM survivor takes the position of rebel, they are silenced by normalisation and surveillance.

However, it is suggested that the third position for the FGM survivor can break this cycle of assessor, victim, and surveillance. Although this position is not intended to repress the panopticon of maternity care, by adopting the position of teacher, FGM survivors can improve the cultural knowledge of health care professionals and shift performance indicators to include culturally sensitive care.

This chapter marks the end of data analysis. The following chapter presents a discussion of the findings that have emerged as a result of this analysis.

CHAPTER EIGHT: WORKING WITH SILENCES (STAGE FOUR)

DISCUSSION

8.0 Introduction

This chapter presents the discussion of the findings following the phases of analysis and contextualises the findings in relation to the aims and objectives of this study as well as the literature reviewed in chapter four. The findings are discussed in two sections within this chapter: (i) the interpreted themes and (ii) the root of silences and the consequences of silences. This chapter concludes with a discussion on the implications for maternity care.

8.1 Themes

This section presents the themes that were interpreted from phases one to three of data analysis. In this chapter the findings from each of these phases have been combined for discussion to facilitate the validation and verification of the results herein. Section 8.1 presents the discussion of the themes that emerged from the data through phases one to three, whilst section 8.2 presents the root and consequences of the silences that emerged following the final researcher review of the data at phase four of the analysis.

8.1.1. Communication

Communication between health care professionals and service users accessing care is crucial to building trust in the relationship; particularly in maternity services when women who have specific needs are accessing care (Gibbon, 2010). The critical review of literature identified that communication is a key concern with FGM survivors

accessing health care service; Ormrod (2019) interpreted this as 'silent suffering' whereby cross-cultural communication was an issue in care experiences. Similarly, the findings from this study suggest that communication plays an intrinsic role throughout the maternity care experience of FGM survivors. Zamani et al (2006) explained that communication is a core component of clinical competence, and a major contributory factor in good clinical practice which can improve the experience of patients; this was evident in the data and expressed in the findings. Throughout the data collection, several forms of communication experiences were reported which are discussed in turn.

(i) Listening

Listening to, and understanding, concerns was reported as a key aspect of the maternity care experience by FGM survivors and one of the most valuable forms of communication. Although Reisel et al (2016) posited that listening to FGM survivors was a crucial component of care, the experiences reported by some FGM survivors suggest that listening and understanding of issues raised by them was dependent on the health care professional's listening skills and understanding of the issues raised. For instance, one FGM survivor described their anxieties at the beginning of pregnancy due to her previous experiences of FGM and requested a planned caesarean section to avoid triggering her PTSD (FS20). However, the woman explained that the midwife she encountered had interpreted this as tocophobia[27] rather than listening to her concerns around PTSD triggers. Whilst mental health issues are central to this experience (which is discussed in detail in section 8.1.3), there appeared to be a lack

[27] Tocophobia is a profound fear of childbirth

of listening skills which affected this woman's experience at the beginning of pregnancy. This finding supports the work of Adelufosi et al (2017) who found that FGM survivors may have varying degrees of mental health and/or psychological concerns; many of which may be spoken about for the first time when accessing maternity care. Listening to, and understanding, these concerns are crucial in care planning to ensure the woman's care is planned to meet her needs.

(ii) Verbal communication

The FGM survivors' experiences of verbal communication were mixed; these experiences were dependent on the health care professional involved with, or providing, the communication. For instance, one woman met with a link worker at the beginning of her pregnancy who shared the woman's cultural background. Whilst the link worker was not a health care professional, the woman explained that the link worker's understanding of the culture surrounding FGM enabled her to explain aspects of her FGM that may impact on her maternity care (FS18). This was a good example of culturally responsive communication and supports the findings of Clark et al (2011).

There were further good examples of effective communication with health care professionals. When procedures were explained in detail, it resulted in women expressing feelings of safety; an example of this was one FGM survivor who described a doctor discussing intrapartum deinfibulation at length which improved this woman's experience by feeling that her fears were alleviated. Another woman required an emergency caesarean section but the reasons were discussed with them beforehand. Two of the women with mental health issues explained that they were asked how they

were feeling during this time which they pointed out had added to their positive experience.

In chapter two, the ontological perspective of critical theory was established as a paradigm for this study. Killam (2013) explained that reality in terms of critical theory is not necessarily concrete and can change depending on interaction with others. Some of the experiences described by FGM survivors supported this theory. For instance, a negative experience prior to pregnancy affected one FGM survivor's perception of health care professionals but their experience of a midwife's communication at the beginning of pregnancy changed the woman's perception of health care professionals in relation to FGM (FS08). This experience suggests that good communication can have a profound effect on FGM survivors' experiences of care.

A common issue with communication was health care professionals discussing the legal position of FGM with the women. When discussing such sensitive information, environment appeared to be a key factor. For instance, one woman described a midwife discussing legal implications with her which led to feeling that others were looking at her (FS14). This suggests that she felt judged by others due to this conversation. Hence care should be taken in clinical areas where there is potential for other patients or members of the public to hear such conversations. This finding supports The Patient Safety Initiative Group (2018) who suggested that the communication environment is a specific challenge and recommended that NHS

leaders should provide private spaces for discussions with patients that include sensitive information.

Further concerns around the communication of legal information were described by FGM survivors. They described midwives informing them that there was a requirement to complete a form regarding concern. One woman described asking the midwife regarding the concern but also that the midwife's reply as 'it was the law' (FS15). Whilst it was impossible to ascertain the midwife's level of understanding of the implications of such documentation, it is probable that the midwife was carrying out the recommendations in the clinical guidance which are informed by RCOG (2015) and further cemented in health care education as presented by Reisel et al. (2016). This appeared to be compounded by the experiences of other women. For instance, one woman felt that 'all they care about is the law' (FS19) while another woman described midwives 'talked more about the law' (FS03). This raised questions regarding communication techniques with FGM survivors and suggests that informing FGM survivors and their families of the legal implications are the most important aspects of FGM guidelines and awareness training for midwives.

Since the guidelines are strongly linked to the measurement of clinical performance, it appears that such discussions are believed to be mandated. For instance, the health care professionals believed that they were mandated to comply with guidelines (HCP06; HCP07) which recommended the discussion of legal implications as part of the pathway of maternity care for FGM survivors (RCOG, 2015). Furthermore, whilst effective communication was considered key in providing care to FGM survivors (HM

Government, 2016; Reisel et al., 2016) there did not appear to be any consideration of the effect on FGM survivors of communicating legal implications in this way as suggested by FS08. This supports the finding that cultural sensitivity appears to be silent in the discourse between FGM survivors and health care professionals and demonstrates that sensitivity appears to be absent in both clinical guidance and health care education.

(iii) Nonverbal communication

Communicating with any patient can be verbal or nonverbal. Bensing et al. (2008) identified that patients would seldom express their emotional concerns verbally but nonverbal expression would provide the clinician with clues for further exploration. Some of the FGM survivors described negative experiences of nonverbal communication with health care professionals. For instance, one woman described the midwife's reaction as 'shock' and 'fear' (FS13), whilst other women experienced being 'rushed out' of their meeting with midwives (FS10). Although it is impossible to determine the actual circumstances during these meetings, nonverbal communication appeared to be central to the women's negative experiences. These findings support those of Evans et al. (2019) who uncovered sentiments by health care professional when reacting to FGM survivors as shock, disgust and horror. Furthermore, these findings seem to emphasise the same notion that is presented in Reisel et al. (2016) but further suggests that such sentiment in health care professional's education is unhelpful and may lead to embedding the same notion in health care professional's understanding of culture around FGM.

(iv) Written communication

Medical records are an intrinsic form of communication between health care professionals which aids care planning and helps to alleviate service users repeating issues (Dingley et al., 2008). The need to document findings from clinical episodes of care is a feature throughout the RCOG's (2015) guideline and is suggested that care plans are documented on a preformatted sheet. Whilst this seems to be an attempt to standardise the documented care planning of FGM survivors, there is a risk that standardising care plans in this way may generalise FGM survivors' care.

However, in instances where information is missing, or medical notes are unavailable, it is imperative that this information is gained prior to assessing a current situation and planning care appropriately. One woman described continually repeating their history to health care professionals which suggests an issue with written communication (FS03). Whilst it was impossible to determine whether information was absent from the woman's medical records or whether the entire medical records were absent, this raised an issue of ineffective communication between health care professionals where written information is key to understanding a woman's needs based on her health and experiences. This also suggests that documentation recommendations from RCOG are not always adhered to.

(v) Information sharing

Information sharing was another form of communication that was an issue raised by the FGM survivors. They felt that the midwives gave little information to them regarding referrals and, in some cases, they felt that the midwives were dismissive; one example

of this was referral to the FGM clinic where some FGM survivors did not appear to be given a reason for referral to the clinic (FS09). During phase two of the analysis, the health care professional groups stated that they had little choice but to refer women to the FGM clinic due to their Trusts' protocols. When questioned regarding the referral process, the health care professionals stated that FGM was not their area of expertise and therefore felt that they had a duty of care to the woman to refer them to the clinic. When further questioned regarding the care plan for the woman following the FGM clinic, most of the health care professionals agreed that the care plans did not differ greatly to care plans for women who did not have FGM.

Ineffective communication can potentially lead to the planning of care that does not meet individual needs; particularly if information sharing and cultural understanding has not been achieved (Nabhan et al., 2012). Nevertheless, during the health care professionals' focus group, one midwife explained that sensitive communication with FGM survivors is important since FGM survivors are perceived as particularly vulnerable (HCP01). In view of this, it was deemed important to refer FGM survivors to the FGM clinic.

Yet the responses of some FGM survivors suggest that adequate information regarding the reason for their referral to the FGM clinic was not shared. Two of the women described that they had little explanation of why they were referred to this clinic (FS02; FS06). However, it is difficult to ascertain the reason for the lack of information provided, but it may suggest that the midwives had little knowledge or understanding of the FGM clinic process. Whilst communication may be a theme in these cases, it is

difficult to draw any definite conclusions due to a lack of information regarding the midwives' knowledge.

There were further examples of ineffective communication involving information sharing during the labour and birth episode of care. For instance, one woman who required deinfibulation during labour expressed alarm regarding the flow of blood following the birth (FS15). This was markedly different to the flow of urine and menstrual fluid that they normally experienced due to their type III FGM. Whilst a midwife explained that the blood flow was normal, the explanation did not alleviate the concern. Although it was impossible to determine this midwife's knowledge of the physiological change following deinfibulation, it may have been pertinent to have provided this woman with the information antenatally when deinfibulation was discussed.

Communicating with FGM survivors is crucial in tailoring care to meet their needs which, in turn, empowers the women to be active partners in their care rather than passive. Yet in Reisel et al. (2016) there appeared to be conflicting information regarding empowerment; on one hand the education package seems to advocate empowerment and on the other hand, 'management' of women appears to be disempowering. Nevertheless, the findings suggest that communication with FGM survivors requires improvement to effectively empower the women in their relationship with health care professionals.

8.1.2. Knowledge and education

When comparing the findings to the critical review of literature, parallels were identified in knowledge and education. For instance, health care professionals reported that training was available which encompasses the types of FGM as well as elements of safeguarding and legal implications of FGM. Although there is online training available from Health Education England as well as the Home Office, the health care professionals felt that training was inadequate. When comparing the findings to the literature, it was noted that education provided by Health Education England and the Home Office focused on clinical (Reisel et al., 2016) as well as legal and safeguarding aspects of FGM (HM Government, 2016; Reisel et al., 2016) but included little or no information regarding cultural competence. As such, the findings from the focus group ratified the critique of health education from the literature. Whilst knowledge and education was inextricably linked with all other themes, it was interpreted that cultural sensitivity appeared to be particularly absent in knowledge and education.

In order for midwives to provide the women with information regarding their care, or the decisions made in relation to any risk assessments completed in relation to their FGM status during the women's initial appointment, midwives required sufficient knowledge and understanding of FGM. However, knowledge and understanding of FGM extends beyond anatomical and physical knowledge; cultural knowledge as described throughout this thesis is required as well as knowledge of effective communication as described throughout this chapter. This notion was raised and ratified during the phases of analysis; particularly by the focus group of health care professionals as well as the subsequent discussion group of FGM survivors.

(i) Cultural knowledge and understanding

Cultural knowledge and understanding is an important factor when providing maternity care to FGM survivors. However, these are symbiotic to health care professionals' education as well as recommendations for care in clinical guidance. The responses from both FGM survivors and health care professionals suggest an absence of cultural sensitivity in clinical guidance and education.

The FGM survivors provided positive and negative responses which encompassed cultural sensitivity and a lack of cultural understanding. Health care professionals' responses appeared to suggest that they lacked cultural competence. For instance, one health care professional pointed out 'we haven't got a clue about the culture […] it's really worrying when you think about it' (HCP04). Another health care professional raised the same concern but linked this with a lack of education of the culture surrounding FGM. These findings support the critical review of literature; in particular RCOG (2015) and Reisel et al. (2016) which have little or no culturally responsive information that would enable health care professionals to provide culturally sensitive care.

When describing FGM survivors, there is an increasing tendency to describe women in terms of belonging to a 'practicing community' (RCN, 2015; NHS, 2017; UNFPA, 2019). Equally, there were experiences described by FGM survivors with health care professionals which suggest an assumption that any member of a society where FGM is prevalent may potentially support the practice. Due to this suggested assumption, some FGM survivors expressed a shift to negativity; including negativity expressed or implied by health care professionals or negative emotions as a result of their contact

with health care professionals. An example of this was one FGM survivor who described an assumption made by a midwife during their first meeting. They explained that the midwife assumed that they lived in a community where FGM was prevalent (FS14). Pulvirenti (2011) pointed out that it is important to have clarity around the background of a patient to avoid any unnecessary assumptions. Therefore in this case, it may have been pertinent to ask the woman whether they lived in a community with others from their country of origin and whether any were from areas that practiced FGM. However, it suggests that information and education on FGM and FGM survivors is generalised rather than approaching each FGM survivor from a personal perspective. Furthermore, this also suggests an ethnic absolutism in health care professionals' knowledge and education of FGM and supports the notion that culturally responsive education is lacking for health care professionals in available training such as Reisel et al. (2016).

When discussing education with the health care professionals' focus group, they explained that cultural sensitivities around the practice, or of the FGM survivors culture is not an aspect of their training or education. Whilst the Health Education England training package refers to sensitive use of the term FGM, there is no further reference to providing culturally sensitive care (Reisel et al., 2016). The HM Government (2016) training package goes further and states that cultural sensitivities must not get in the way or detract from the seriousness of FGM. Whilst the intention might be to prevent and protect minors from potential FGM the message suggests that cultural sensitivity is unimportant. This was evident in the findings where health care professionals explained that they receive little or no culturally informed education on FGM (HCP03;

HCP04) and suggests a gap in cultural dissonance with FGM survivors which increases the risk of providing culturally insensitive care.

The findings further suggest that disregarding the cultural sensitivity aspect of providing care to FGM survivors overlooks one of the most important elements of training that will provide professionals with the tools to empower FGM survivors during their care. As such, cultural care has been interpreted as a silence in the data. It appeared that this silence of cultural sensitivity extended to policy and guideline recommendations as well as FGM awareness education; this is discussed in section 8.2.

Understanding the cultural drivers intrinsic to FGM and sensitivity to the culture is imperative to the education of health and social care professionals involved in maternity care who, according to NHS Digital (2017), provide the majority of care to women who live with FGM. Nevertheless, it cannot be overlooked that fear of prosecution can be a powerful tool in preventing action or inaction of illegal procedures; this may be the rationale for the absence of cultural sensitivity in education, training and clinical guidance. However, instilling a fear of prosecution into FGM survivors within a care environment can potentially create an imbalance of power within that relationship and disempower the woman which can potentially lead to further silencing the FGM survivor.

Two FGM survivors described accessing deinfibulation services prior to pregnancy; both experiences provided care that was culturally insensitive (FS08; FS18). Naturally, genital inspection is required to assess the genitalia prior to performing the

deinfibulation procedure and is supported by RCOG (2015). However, these women originated from cultures where exposing any part of their bodies was outside of their cultural norm. Both of these cases support the work of Clark et al. (2011) who stated that the provider and patient should share the same philosophies in health care. It is imperative that health care professionals who provide care for women with FGM have comprehensive knowledge of the social and cultural context of FGM that can symbiotically affect the woman's physical, psychological and emotional health and well-being and therefore impact on the care that women receive. This presented a cultural divergence which required understanding from the health care professionals. As a result, the women's experiences of care were negative; subsequently, this affected one woman's perception of maternity services (FS08).

Providing care to FGM survivors requires an understanding and awareness of the culture that surrounds FGM but also an understanding of what appears to be a cultural shift taking place within the communities that have historically practiced FGM. In countries where FGM is historically and contemporarily practiced, there are some suggestions of a cultural shift to reject FGM (Lancet, 2018). During the one-to-one interviews, the FGM survivors unanimously rejected the practice which, whilst this was a small sample, further suggests that a cultural shift is taking place. For instance, one of the women had renounced their family in order to protect any daughters that they may have (FS05). The FGM survivors were aware of the law and were proactive in the principles of the protection of any girls from experiencing FGM and living with the experiences that many of the women had already encountered.

Nevertheless, this proposed cultural shift, in comparison to the historical culture of FGM, is a potential new culture which may take decades to embed into the societies to end the practice. Furthermore, this potential timeframe falls short of the pledge of the coalition government in 2014 and the aims of the Girl Summit which mandated to end the practice in a generation. Still, it is imperative to nurture any suggestion of a cultural shift despite the coalition government pledge and not assume that all individuals from societies that practice FGM will perpetuate the practice. Furthermore, this appears to give credence to resist using the term 'practicing communities' within the UK since this suggests ethnocentrism and an ethnic absolutism perspective of FGM survivors.

The knowledge of FGM that was identified during the literature review supports this perspective; particularly in relation to Clark et al. (2011) and the discourse between the FGM survivors and the health care professionals. Furthermore despite repeated recommendations in local and national policies and guidelines, as well as education tools, that fear of cultural disparity should not deter a professional from questioning women regarding FGM, there remained an acknowledgement that potential ethnocentrism was a factor in their approach to FGM survivors (HCP05). The midwives pointed out that a lack of education around cultural knowledge affected their communication with FGM survivors and impacted on the initial relationship with them and their families. However, none of the FGM survivors or health care professionals reported or alluded to ethnocentrism as a result of receiving or providing maternity care.

However, there appeared to be differences of culturally sensitive care dependent on the health care professional as well as the clinical environment. For instance, one FGM survivor described their experience of feeling profound cultural insensitivity in the FGM clinic by describing that they felt like a ‘criminal and a piece of meat’ (FS19). These feelings were expressed following the woman reporting that they felt pressured by a doctor into a visual examination of their genitalia. The woman originated from a culture where exposing the body, particularly intimate areas of the body, was outside of their cultural norm. Although genital inspection is recommended by RCOG (2015), feeling pressurised into genital examinations may lead to profound cultural insensitivity and may lead to psychological and/or emotional harm which was described by FS19. Hence, improving cultural knowledge and understanding in training and guideline recommendations may improve the experiences of FGM survivors and alleviate the feeling of cultural insensitivity during care episodes.

However, in contrast to this, care experiences with midwives were described positively which suggests that some midwives have a deeper cultural knowledge of FGM. For instance, one woman described initial fear at the prospect of attending the clinic but they explained that the midwife showed them pictures to avoid a genital examination (FS16). In contrast to the women examined by the doctors, it appears that the midwife achieved culturally sensitive care. Another woman described a midwife supporting their decision for a planned caesarean section despite the doctors being against it (FS20). This woman described feeling empowered in their decision by the midwife who acted as her advocate in this instance. A further woman described that their feelings changed by attending the FGM clinic; their initial negative experience with a midwife

at the beginning of pregnancy resulted in their experiencing fear at the prospect of attending the FGM clinic.

The lack of cultural sensitivity and understanding led to a discussion on colonialism and a notion that health care professionals may be seen as ‘interfering in something we don’t know about’ (HCP05). Although one health care professional disagreed with this, they did concur with other health care professionals in the group who felt that cultural knowledge on FGM was lacking in health care education. However, this notion supports Njambi's (2004) view that anti-FGM movements are a construct of colonialism. As a result, health care professionals expressed difficulties in providing care to FGM survivors. This was an interesting point which resulted in a link to knowledge and education around providing cultural care to FGM survivors and a silence heard in the dominant discourses which is discussed in section 8.2.

8.1.3. FGM and Mental Health Care

Mental health issues and the care provided to women who experienced these was an important theme interpreted from the data. Knight et al. (2015) identified one quarter of all maternal deaths between six weeks and one year after childbirth were related to suicide as a result of mental health concerns; RCOG (2017) pointed out that 40% of these deaths may have been prevented by improvements in care. As a result, the NHS Five Year Forward View for Mental Health (FYFVMH) stated the objective of supporting at least 30,000 more women each year to access specialist perinatal mental health care by 2021 (NHS England, 2016).

Mental health issues of FGM survivors appeared to be a particularly challenging issue amongst health care professionals which was closely linked with their knowledge on FGM and mental health. However, there was suggestion from one health care professional regarding a 'joint clinic' (HCP02) which may alleviate the disjointed services within maternity around mental health of FGM survivors.

Equally, the FYFVMH pointed out that multi-disciplinary team are vital with key relationships being with maternity, obstetrics and health visiting. In accordance with this, the research site employs a dedicated midwife for women with mental health concerns. Whilst there was an element of mental health training at the research site, albeit in the form of e-learning, there was no training which encompassed mental health as either a direct or indirect result of FGM (or vice versa). The women were referred back to their GP in order for a mental health diagnosis and then for referral for treatment due to the FGM specialist midwife having no mental health training or experience in this area of expertise. Equally, the specialist midwife for women with mental health issues had only online training knowledge of FGM which did not encompass mental health training specific to FGM survivors. It appeared that FGM and mental health were separately compartmentalised with no recognition of an association between the two. Furthermore, these findings supported those in the FYFVMH which suggested that there had been no improvement in the mental health care of people from BAME backgrounds since the Five year Delivery Race Equality programme (2010).

This appeared to be evident during the focus group of health care professionals. When questioned regarding the direct and indirect mental health implications of FGM, the

health care professionals did not believe that it was within the remit of the FGM service to provide mental health care and assessment and, as recommended in local maternity guidelines, the woman should be referred to a GP for mental health care management. This supports the notion of a disjoint in maternity care and mental health care and a lack of improvement in BAME mental health care as stated in the FYFVMH (NHS England, 2016). Furthermore, due to the lack of knowledge and understanding of the potential association between FGM and mental health issues, there appeared to be an association with the themes of knowledge and education, service provision and was equally related to the interpreted silences of cultural sensitivity and providing cultural care.

During the focus group, many of the health care professionals described their duty of care that related to FGM survivors; this duty of care related to safeguarding and consent. This was in line with statutory regulation which are provided by NMC (2018a). Yet, there appeared to be an overwhelming blame culture identified; particularly around safeguarding. For instance, one health care professional described “children slipping through the net” and alluded to blame being apportioned to those who had not referred them to safeguarding (HCP02). This also supports the critique of the health education which suggested a victim-centred approach and a totalitarian view of safeguarding (Reisel et al., 2016) and Home Office training with the notion of disregarding race in relation to care (HM Government, 2016).

The first point of contact for the FGM survivors at the beginning of pregnancy was with a community midwife. Local guidelines recommended that all women were questioned

regarding their FGM status regardless of ethnic origin. All of the women in the FGM survivor group were identified as FGM survivors at their first meeting with their community midwives. On confirmation that the woman had experienced FGM, referral took place to the FGM clinic which is specifically aimed at planning care for FGM survivors and existed within a group of services termed as 'vulnerable women services'.

8.1.4. Service provision and statutory regulation

Service provision emerged as a theme from both the FGM survivors and the health care professionals which related to pre-pregnancy as well as maternity care. It appeared that experiences of maternity care had a profound effect on FGM survivors' perceptions of service provision and health care professionals in maternity services; this included pre-pregnancy care.

(i) Pre-pregnancy experiences

Four FGM survivors provided insight of their experiences of services prior to pregnancy. These experiences related to deinfibulation services in London; therefore, all of these FGM survivors had experienced a type III FGM. None of the women lived in London at any time so explained that access to these services was particularly challenging. None of the women were aware that there was a deinfibulation service local to the research site that was established over 20 years ago which suggests that there is no accessible information regarding available services in the local area. However, none of the women had discussed pre-pregnancy deinfibulation with their

GP due to expressing discomfort discussing such matters which also suggests cross-cultural communication sensitivities.

Nevertheless, the FGM survivors highlighted poor access to services for FGM survivors for care outside pregnancy. When discussing these issues with the health care professional group, they said they thought that specific services for FGM survivors are required in all areas. For instance, one health care professional believed that such services were 'niche' so was not an NHS spending priority (HCP07), while another health care professional believed such services were concentrated in areas where they were needed (HCP06). Yet the literature review uncovered that geographical areas where FGM had not been traditionally recorded are now recording FGM survivors in their dataset which is reported to the NHS Digital (NHS Digital, 2018). As such, it is feasible that FGM survivors may access services anywhere in England and Wales. Nevertheless, where specific services are not available for FGM survivors, FGM related services are integrated with maternity services; predominately under the umbrella of vulnerable women. As such, FGM survivors are routinely referred to vulnerable women services which implies that all FGM survivors are vulnerable. This was confirmed with both the FGM survivors and health care professionals during the data collection period.

(ii) Maternity services

During pregnancy, services provided to FGM survivors exist under the umbrella of vulnerable women services. These services include care such as genital examination for women with type III FGM who may benefit from deinfibulation, with doctors

available for women who had complex needs. This raised a question with one health care professional regarding mental health care who believed that mental health counselling should be more specific for FGM survivors; such as trauma counselling (HCP05). This discussion did not provide any conclusion regarding the provision of services for women outside of pregnancy yet it did raise concerns regarding mental health services for FGM survivors which were addressed in section 8.1.3.

(iii) Culture of maternity services

Issues around institutional culture were important findings which appeared to be linked with service provision and regulation. The health care professional's focus group unanimously felt that there was an expectation that they follow recommendations in guidelines in the same way as standards in policies. For instance, one health care professional pointed out that they 'don't have a choice whether we follow guidelines or not' (HCP06), while another health care professional believed that guidelines must be 'followed to the letter' (HCP07). During the literature review, it was found that the evidence in RCOG (2015) guideline appeared to be unreliable, although one health care professional pointed out that guidelines should be followed because the evidence within these have 'proved that this is the best thing to do' (HCP09). Furthermore, the health care professional who pointed out that guidelines should be 'followed to the letter' (HCP07) also pointed out that guidelines are scrutinised during investigations to ensure that the recommendations have been followed precisely. Furthermore, an analysis of the discourses suggested that health care professionals assume the role of assessor in the discourses due to their dependence on education from HM Government (2016) and Reisel et al. (2016) as well as their dependence and accountability to follow guidance from RCM, RCN, RCOG, Equality Now (2013) and

RCOG (2015). Although the discourse extracted from guidelines is discussed in section 8.2, it suggests that health care professionals are institutionalised to comply with recommendations in guidelines that are conceived from evidence that is unreliable.

There was further suggestion of this institutional compliance relating to statutory regulation. The NMC (2018a) standard relating to professional and ethical practice refers to guaranteeing care that meets with a woman's (and her family's) cultural beliefs and preferences. Yet the following standard relates to practising in accordance with relevant legislation; including a demonstrable knowledge of contemporary ethical and legal issues that may impact on midwifery practice. This presents an enigma with FGM since despite this being a cultural issue, it has been illegal in England and Wales since 1985. Furthermore, when examining NMC (2018b) cultural sensitivity was only mentioned once in relation to communication methods and not related directly to practice and service provision. As a result, it is suggested that this might lead to health care professional's vulnerability in cultural knowledge, understanding and provision of care to FGM survivors.

Yet, Nishida (1999) and Noelle-Neumann (1993) can provide some insight into the health care professional's suggested vulnerability regarding FGM survivors with the application of the cultural schema theory and spiral of silence theory. The cultural schema theory describes how cultural information is organised by increased information and interaction between like-minded individuals; this can be applied to the western society cultural interpretation of FGM which is rooted and organised in the

education of health care professionals as well as the requirements that have been mandated in changes to legislation. In addition, Noelle-Neumann (1993) spiral of silence theory can explain how dominant cultures may view other cultures as 'deviant'. As such, the dominant cultures 'silence' the deviant cultures through misrepresentations to the wider public. Hence public opinion, organisations, individuals and even governments may ratify such silences; this is discussed in section 8.2.

8.2 Silences: The root and consequences of silence

The themes interpreted from the data have been discussed in the preceding section of this chapter. However, phase four of the analysis interpreted 'silences' from the data which seemed to transcend each of the themes.

The silences that emerged from the literature related to cultural knowledge, power and vulnerability which appeared to be associated with the interpretation of FGM in the Hosken Report. The final researcher review at phase four of the analysis presented the interpretation of dominant discourses in the data. This analysis led to the interpretation of silences in the maternity care of FGM survivors as well as the provision of care by health care professionals. Furthermore, it is not the intention to argue *if* the FGM survivor's vulnerability exists because it *does exist*, the intention is to argue the *consequences* of this silence and how to work with these silences to provide possibilities to improve the care for FGM survivors.

The roots of the silence around cultural sensitivity have been traced to the language and interpretation of the practice in Hosken (1979) which has been ratified, and thus

far unchallenged, in literature, education and clinical guidance. The findings from this study suggest that this interpretation has persisted in contemporary studies, education and clinical guidance and may have had a detrimental effect on the care experienced by FGM survivors. For instance, one woman described a midwife's assumption that they lived in a community with other FGM survivors (FS14) whilst another woman described a midwife telling them that another member of their community might perform FGM on their child (FS15). These notions appear to relate to the training packages available to health care professionals, particularly the Home Office training package, which suggests that cultural sensitivity should be ignored. This appeared to be further exacerbated in the postnatal period when some women described insensitivity around discussions; such as FS14 who felt that other postnatal women could hear the midwife discussing the legal implications of FGM with them. However, HCP02 suggested that women are "scared to talk about it" which suggests that health care professional believe all women have internalised a victim agency in relation to their FGM. This notion appeared to be ratified with comments from HCP04 who stated that women have no choice in their referral to vulnerable women services. This suggests that health care professionals view that all FGM survivors are vulnerable and victims and supports the critical review of Evans et al. (2019) and Ormerod (2019) which suggested that health care professionals have an ethnic absolutist view of FGM survivors. As such, it appears that the health care professionals have been silenced in the discourses by an outdated and unchallenged outsider interpretation.

Whilst the culture of care in maternity is to maintain dignity and challenge discriminatory attitudes and behaviour (NMC, 2018b), phase four proposed that health care professionals have become risk assessors in the maternity care discourse of FGM

survivors. Although clinical guidance *recommends* aspects of care, NHS Trusts use audit to measure the compliance to such recommendations to ascertain the overall quality of care provided. This was evident in the data such as the comment by HCP06 who suggested that health care professionals are mandated to follow recommendations in clinical guidelines and confirmed by HCP09 in terms of following guidelines to ensure that FGM survivors understood implication of FGM. This suggests that NHS Trusts use recommendations as instructions which must be adhered to. Since cultural care was silent in the literature, education and guidance, it is suggested that the health care professionals were silenced as a consequence.

Equally the findings from the health care professionals suggested that they were unable to take up the position of carer in these discourses due to such surveillance, observation and scrutiny of the care they provided. As such, despite the position of carer being available to health care professionals from which to speak, they appeared to consistently speak from the position of assessor in the discourse of antenatal risk. When comparing maternity service provision to Foucault's (1977) interpretation of the panopticism, it appeared that maternity care is under constant surveillance, and observation by regulatory authorities using strict performance criteria and indicators. This was evident in HCP01's comment which suggested that disciplinary procedures would be instigated if clinical guidance was not adhered to. As a consequence, whilst the position of carer exists, it appears that it is not available to health care professionals in the discourses. Yet this was linked to the interpretation of silence of culture.

The silence of culture around FGM seems to prevent midwives from providing dignified, culturally responsive care to FGM survivors. As a consequence, it appears that FGM survivors feel judged due to the implied importance of the legal implications of FGM and the connotations of the victim-perpetrator philosophy in maternity care. Likewise, the perpetuation in the victim-perpetrator philosophy in wider multi-agency guidance and education serves to cement the silence amongst the health care professionals.

In parallel to the silence of cultural sensitivity and understanding, the silence of vulnerability emerged. The root of this silence appears to exist due to the proposed vulnerability of health care professionals with their lack of cultural knowledge and understanding, but also as a result of their position in the discourses. For instance, it appeared that health care professionals were expected to provide care and health education to FGM survivors, as well as instigate referral pathways, without understanding the cultural implications or having knowledge of cultural sensitivity (HCP03; HCP04). The consequence of this silence was the care that FGM survivors experienced during their maternity care. Whilst this silence is rooted in education, guidance and ultimately from the interpretation of the practice by Hosken, it manifests in health care professionals due to the only position that appeared to be available to them is that of assessor. As a consequence, it is suggested that the health care professionals are perpetually vulnerable whilst caring for FGM survivors. Whilst the expectation is for health care professionals to provide culturally sensitive care (NMC, 2018b), there appears to be a gap in cultural knowledge to provide such care and the position of carer appears to be closed to them within the discourses due to surveillance and observation within the maternity care panopticon.

Hence it appears that the health care professionals are providing care to a cohort of women in maternity service without adequate knowledge and without no position of carer from which to speak. Furthermore, it is suggested that the consequence of this perceived vulnerability is that FGM survivors are receiving care that may not, and as suggested in the data does not, meet their needs. As such, it is further suggested that FGM survivors may experience care that would cause harm. This notion was voiced by HCP08 who suggested that the lack of mental health support might have caused further damage to womens' mental health. Ultimately, this proposed silence of culturally responsive care potentially projects from the health care professional to the FGM survivor. This silence mirrors the silence of cultural sensitivity since the suggested lack of, or disjointed, mental health care in maternity services for FGM survivors may cause harm due to the lack of understanding and/or knowledge.

The silence of culturally responsive care appeared to expose the health care professionals' silences but the FGM survivors' silences were interdependent and rooted with these. Phase four of the analysis uncovered that FGM survivors have three position from which to speak in the discourses. Since the health care professionals appear to be forced to speak from the position of assessor in the discourses, the FGM survivor takes the position of victim or rebel. When speaking from the position of victim, they are forced to accept totalisation and adapt into the maternity panopticon. As a further consequence, FGM survivors are continually assessed and objectified and assimilated into western society culture since their own culture has been silenced. Conversely, when speaking from the position of rebel, it appears that they are exposed to negativity from the health care professional since it suggests that they impede the health care professional's assessor role which is equally under surveillance and

observation within the maternity panopticon. However, the third position, that of teacher, may bridge the gap between the positions of victim and rebel as well as facilitating the health care professional's movement into the position of carer in the discourses and voicing the silence in the literature.

8.3 Chapter summary

This chapter has presented the discussion of the findings from the collected data and reconciled these with the findings from the literature. The data uncovered that power, agency and vulnerability were important discursive objects which affected both the care that FGM survivors receive as well as the care provided by health care professionals. Through analysing the power, agency and vulnerability in the discourses, it was uncovered that vulnerability was a silence that has embedded into statute, education and clinical guidance. However, whilst the health care professionals were the root of vulnerability, this vulnerability was projected onto the FGM survivors, which ultimately constructed their vulnerability. Furthermore, it has been argued that the *silence* does not indicate that a person or group of people are 'silenced' or silent, but the silence is what has not been said, interpreted or understood.

The following chapter concludes this thesis with the presentation of the new knowledge produced as a result of this study as well as the rigour, limitations and recommendations that have resulted from the findings discussed in this chapter.

CHAPTER NINE: PLANNING FOR SILENCES (STAGE FIVE)

CONCLUSION AND RECOMMENDATIONS

9.0 Introduction

This chapter concludes the study by summarising the key points from the literature and comparing these with the findings from this study to consider whether the aims and objectives of the study have been met. Furthermore, this chapter presents the contribution to knowledge that this research provides which includes a conceptual model of cultural silences. In addition, the limitations and risks are presented and how these were addressed prior to, and during the study. Furthermore, the rigour of the study is presented in this chapter with reference to the qualitative nature of the research. The chapter concludes with researcher reflection on the sound of silence framework and the recommendations arising from this study.

9.1. Summary of the study aims, literature review and findings

The aims of this study were to explore the experiences of FGM survivors accessing maternity services as well as an exploration of health care professionals' experiences' of providing care to FGM survivors. The third aim of the study was to explore the language used when providing care to FGM survivors and whether this had any impact on the care that was experienced.

The critical review of literature revealed the majority of evidence that supports guidelines and education of FGM is conducted, interpreted and presented by outsiders of the practice and culture. When comparing this knowledge with studies conducted

with cohorts from inside the culture, there appeared to be a misunderstanding of the drivers for the practice of FGM which resulted in a misrepresentation of the practice as a method of patriarchal control and power. This interpretation of patriarchy seems to have woven into the knowledge of FGM in western society and its perpetuation appears to have resulted in the perspective that FGM survivors are victims of patriarchal control. When comparing this finding to the education and clinical guidelines available to health care professionals to provide care, there appears to be a consolidation of this knowledge with a focus on the legalities of FGM with a victim-centred philosophy.

However, when comparing the findings of the literature review to the study findings, it appears that this knowledge, which has embedded in education, guidelines and available research, seems to have resulted in a culturally insensitive approach to FGM survivors in maternity services and health care professionals' inability to provide culturally responsive care. Furthermore, the strategic aims of the maternity services are to meet performance indicators (as monitored by the CQC) and as such measure health care professionals' competencies and responsibilities of providing legal advice to FGM survivors on the practice of FGM. Furthermore, mental health care for FGM survivors who were accessing maternity care appeared to be a significant issue and one that seemed to be overlooked.

9.2 Contribution to knowledge

This study has identified a relationship between silence and culture which provides a foundation for a conceptual model of cultural silence. This was evident in the silence

of cultural sensitivity in maternity care discourses; particularly when FGM survivors described feeling compelled to expose their genitalia for inspection (FS18). As such, this study contributes to knowledge by contributing to the wider context of maternity care provision to FGM survivors and uncovering cultural sensitivity in maternity care. This study further contributes to the education of health care professionals on the awareness of FGM and the formation of policy and guidelines relating to the care of FGM survivors.

9.2.1. The culture of silence around FGM

At the outset of this study, it was believed that silences existed around FGM; whether this was intrinsic to the practice itself or the women's views of their care. This corroborated Serrant-Green (2011) notion and the rationale for using the silences framework which was discussed in chapter two.

During the data collection and analysis stage, it was uncovered that silences appeared to manifest prior to, and throughout the sphere of care of FGM survivors; but this study uncovered that the silences were not solely conceived by the FGM survivors. The findings from this study concluded that silences were constructed in the subject positions within discourse that were rooted in ethnocentric interpretations of FGM and embedded in statute, clinical guidance, education and research.

Despite the marked increase in awareness of FGM and the education mandate surrounding FGM, the silence culture appeared to be symbiotic to the subject of FGM

as a whole. Yet, intrinsic to the culture of silence surrounding FGM was an embedded power imbalance within the relationship between the FGM survivor and the health care professional. This was evident in studies such as Evans et al. (2019) where clinicians attempted to take control, in health care education such as Reisel et al. (2016) where the demonstration of care provision in formative assessment of knowledge suggested that health care professionals should “deal with patients with FGM” and in Ormerod (2019) with the concept of “silent suffering”. The findings in this study support the critical review of literature by suggesting that FGM survivors are vulnerable (HCP01) and require extra support but expose the silence of inability to provide culturally responsive care (HCP03; HCP04). Whilst the structure of the silences framework, combined with analysing discourse in the data successfully facilitated in hearing that which was unheard, there is further scope to build on this by creating a model to identify the root causes of silences in cultures such as those identified throughout this thesis.

Two key components can be combined to facilitate a foundation to such a model; Nishida (1999) cultural schema theory and Noelle-Neumann (1993) spiral of silence theory. Nishida (1999) provided insight into the formation of culture through shared values and concepts which appears to be inherent in each culture. Furthermore, this aligns with Reiss (2002) theory of religious affiliation which posits loyalty to parents, ethnic groups and heritage. The cultural silences model builds on the silences framework by considering how the root causes of silence have manifested in discourse. By capturing the foundations of cultural schema theory (Nishida, 1999) and combining this with the spiral of silence theory (Noelle-Neumann, 1993), this may expose cognitive and cultural dissonance between one culture and another.

The first stage in this model provides a platform where cultures are already established and have been integrated into cultural heritage as described by Nishida (1999). Stage two encompasses interaction with a culture that is outside of the established culture which has different, or opposing, views, values, opinions and beliefs. At this point, discursive objects may be formed and discourse commence between the cultures to establish connection and/or understanding of the concepts of the culture.

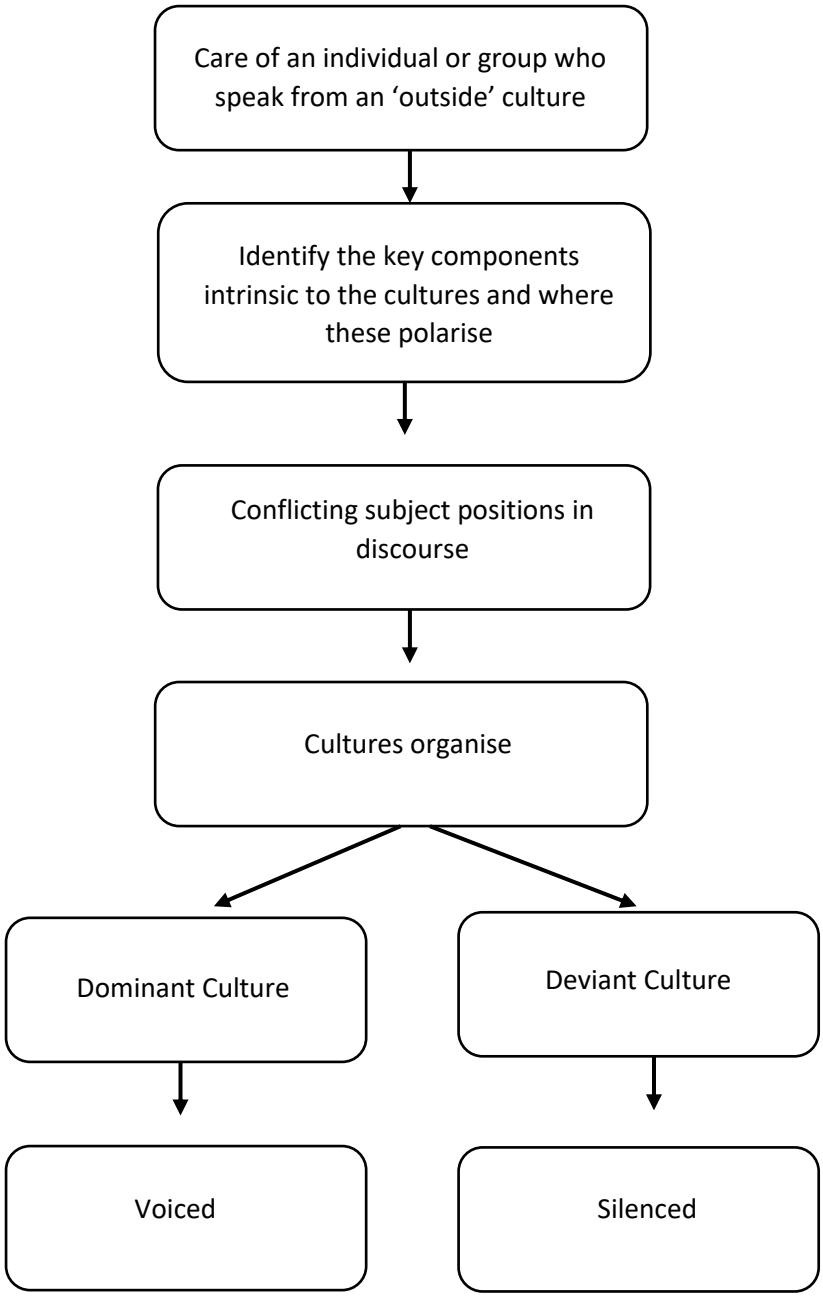

Figure 15 Model of Cultural Silence

However, during the discourse between the cultures, ethnocentrism may be introduced by using each culture's own values, opinions and beliefs which may not align with the unknown aspects of the new culture. Where a culture is dominant, discourse may become misaligned or silent due to misunderstanding the foundational reality of the opposing culture. As a result, the dominant culture may misinterpret the opposing culture which may then be defined within the context as deviant. Using the basis of the spiral of silence model, the deviant culture may then be misrepresented through dissemination of knowledge. As a result, the 'deviant' culture may then be silenced by public opinion, organisations, individuals or governments; or even by the culture itself.

9.2.2. Wider context of maternity care for FGM survivors

This study identified gaps in the knowledge of health care professionals which had an impact on the maternity care experience of FGM survivors. This was interpreted from the data collected during the health care professional focus group. For instance, HCP03 described the available training but concluded that it did not provide any cultural context to the care that should be provided. The FGM survivor discussion group ratified this finding by suggesting that health care professionals have no knowledge of providing cultural care to FGM survivors (FS02). While care provided to FGM survivors may have fulfilled physiological needs, there was a lack of cultural understanding and awareness amongst health care professionals. The education that was freely available had a predominant theme of the illegality of FGM and the existing research was predominately focused on the health care professionals' perspective in maternity care rather than the FGM survivor. This was subsequently reflected in guidelines as well as campaigns aimed at reducing and ultimately ending the practice.

Therefore, there are two original contributions resulting from this context:

- The identification of a predominately legislation and outsider focused care provision for FGM survivors which is a principal theme in the current provision of health care professional FGM awareness training.
- Cultural sensitivity for FGM survivors is absent from maternity guidance, education and service provision.

9.2.3. Mental health care in maternity services for FGM survivors

There were a number of mental health complexities described by women participants with living with FGM. These ranged from PTSD (FS20) and differing levels of mental health issues, to difficulties with communication and disparity of understanding between themselves and their health care providers. Whilst the literature and evidence in this area of care for women who live with FGM is growing, there is still very little evidence or information from FGM survivors with mental health concerns who access maternity services or cultural competence amongst health care professionals who provide maternity care. Women who disclose mental health problems during pregnancy are referred to the mental health team within the maternity service who assess their needs, plan and implement the care of the women during their need for perinatal care. However, the FGM survivors who disclosed mental health concerns were referred to their GP for mental health care. Yet, FGM services are fostered alongside mental health services within maternity service under the umbrella of vulnerable women. Therefore, FGM survivors who may experience mental health concerns should be provided the same, or further specialised, mental health care that women who have not experienced FGM are provided with.

Hence there are three contributions to knowledge that related specifically to mental health care of FGM survivors in maternity services:

- The provision of mental health care for FGM survivors is not seamless within the sphere of maternity care
- Education on mental health care for FGM survivors is lacking in FGM awareness education
- Clinical guidance on FGM does not encompass mental health care and clinical guidance on maternal mental health does not encompass mental health care of FGM survivors.

9.2.4. Opportunities for education and guideline development

One of the objectives of this research was to explore the knowledge and understanding of FGM amongst health care professionals who provide care to FGM survivors.

The key contribution in relation to this objective was the identification of the gap in care which related to cultural awareness. The FGM survivors identified an opportunity for improving education and policy development by co-designing educational tools for FGM awareness training with health care professionals and FGM survivors. Developing health care professional knowledge in this way can potentially improve engagement with FGM survivors which in turn can potentially improve identification of FGM survivors which may ultimately lead to an improvement in the care that they receive. Furthermore, this may lead to improved prevalence rates which may lead to better-quality service provision for FGM survivors. Potentially, this may also address the vulnerabilities of health care professionals in delivering care to FGM survivors.

Hence there are two contributions to knowledge from this section:

- The experience of maternity care for FGM survivors is dependent on the knowledge of the health care professional providing care
- Health care professionals' lack of understanding of FGM seems to result in their vulnerability when providing care for FGM survivors.

9.2.5. Methodology

This study adopted the silences framework to underpin its structure. The unique contribution is that this framework has not been used to underpin doctoral research in a maternity setting with a marginalised group of women who are considered to be vulnerable.

Therefore, the methodological contribution to knowledge was the testing of the rigour of the silences framework, utilising it as a foundation to conducting research with a marginalised group within maternity services. In addition, the silences framework was utilised to underpin the elements of the research that identified the potential vulnerabilities of FGM from the perspective of both the FGM survivors and the health care professionals.

The experiences of the FGM survivors, as well as the health care professionals, required an anti-essentialist perspective and a robust framework to support the study. The silences framework accepted that reality is not objective or fixed but is influenced by people in societies at a particular point in time (Williams and May, 1996). This

concept was evident in the identification of the themes from the FGM survivors where poor communication and insufficient health care professionals' knowledge led to care deemed inadequate by the FGM survivors.

In addition, the silences framework enabled adaptation of the methods for data collection and analysis which were crucial in the uncovering of silences within this research. Thematic analysis was completed for phases one to three to uncover themes in the data, whilst the fourth phase of analysis consisted of a discourse analysis which was central to the exposure of silences. Since power was uncovered in the literature and discourses, this was highly compatible with the silences framework in uncovering and analysing discourses of marginalised and silent groups.

Furthermore, the silences framework was strengthened for this study during the phases of analysis by modifying it from its original model. This adaptation gave the FGM survivors an opportunity to respond to the findings from the health care professional group. In doing so, the FGM survivors were given insight into the rationale that health care professional gave for the care they provided but this also gave the FGM survivors a chance for their voices to be heard in response to health care and to offer solutions to the gap in health care professional knowledge.

9.3 Rigour

Evaluating the trustworthiness of studies is an important pre-requisite (Long and Johnson, 2000) in establishing that the research design has met the objects as well as the findings being credible, transferable and valid. Guba and Lincoln (1994) addressed

the concept of rigour of qualitative studies by replacing terms synonymous with quantitative data in order to demonstrate the trustworthiness of study outcomes. However, Ali and Yusof (2011) suggest that the test of the quality of qualitative research is implicit to the trustworthiness of the research design and not the outcomes. The rigour of this study will therefore be addressed at this point using Long and Johnson (2000) approach.

9.3.1. Reflexivity

Long and Johnson (2000) point out that reflection is a crucial element of qualitative research practice. Indeed, reflection has been a core element of this research from its conception. Continual reflection throughout the research process facilitated the construction of the methods by attempting to reduce dissonance from the outset in researcher identity. These included cognitive and cultural dissonance, particularly due to outsider education and the professional requirements in statutory regulation. For instance, modifying the phases of analysis so that FGM survivors were able to respond to the findings from the health care professionals in stage three of the silences framework. Yet, reflecting on cultural dissonance led to conceiving and maintaining a reflective journal throughout the process. The journal provided a space to reflect on a multitude of areas, particularly on personal views and participant sampling and the use of the silences framework which has culminated in the presentation of such reflections in this chapter.

9.3.2. Validation and member checking

The silences framework was crucial in the validation of findings; particularly with the phases of analysis. I completed the initial review of the data which culminated in the initial themes from FGM survivors. The concepts of these themes were then reviewed by health care professionals who, by virtue of their roles, had experience of working with FGM survivors. This provided an initial layer of validation of the interim findings. However, further validation took place by FGM survivors who were involved with the initial data collection interviews. Hence a group of the initial participants were given the opportunity to revisit the findings as well as a validating any further findings as a result of phase two. Furthermore, I revisited the findings in their entirety at the end of the phased analysis.

9.3.3. Prolonged immersion in the field/prolonged involvement

The concept of this study was born from my own professional involvement with FGM survivors. As a student midwife, I had developed an interest in the subject of FGM and when qualified as a midwife provided support and knowledge to student midwives as well as midwives on FGM. Equally, I provided care and support to FGM survivors in the clinical area as well as support to other clinicians providing care to FGM survivors and their families. At the end of data collection, I had accrued ten years of work with FGM survivors.

9.3.4. Debriefing

Long and Johnson (2000) pointed out that discussing emerging findings with knowledgeable colleagues is a key role in strengthening rigour within a study.

Supervision was an important component in rigour for this research as my supervisors are experienced researchers in both public health and vulnerable groups. Sharing chapters intermittently with my supervisors provided me with valuable feedback throughout the research process which enabled me to strengthen my methodology, findings and the structure of the research overall.

Furthermore, and in addition to forwarding drafts to supervisors, regular meetings were held with supervisors to discuss forthcoming actions within the study as well as review actions that had been carried out. Agendas were drafted for each meeting, with meeting minutes compiled following these. By doing so, this enabled progress to be reviewed and amended (where required).

9.3.5. Transferability

Thomas and Magilvy (2011) explain that transferability in qualitative research is to present the description of either the methods, the findings or both in a comprehensive way so that these can be transferred from one group to another. As such, this study has clearly described the need for the research, the context of the study and where the participants were situated within the literature and study, the inclusion and exclusion criteria, the methods of data collection and analysis how the underpinning structure and theories of the study. These clearly were clearly presented in sufficient details and were verified by supervisors so that independent evaluation and transfer to other settings could be achieved.

9.4 Limitations

During this study, several limitations were encountered which is addressed here. The most anticipated problem during the planning stage of the study was of identification of the sample. When initially writing the proposal for this study, the researcher's main employment was within the maternity inpatient environment; which enabled identification of participants who had agreed to take part in the study. But employment changes, to facilitate the study, meant that the researcher was no longer working in the inpatient environment, but in the governance department which minimised patient contact. This became problematic when attempting to identify women who accessed maternity services. Identification of potential participants then relied heavily on the midwives in clinical areas.

The research site held a regular clinic that was specific to women who were FGM survivors. Women were referred by their community midwife to the FGM clinic once identification had taken place. It was believed that this would have provided a potential platform for recruitment of participants. Invitation letters and participant information sheets were available to all members of staff who provided care to the women in the specialist clinic. In addition, further information was given to the members of staff who regularly facilitated the clinic. Meetings were held with link workers who were employed by the Trust to facilitate communication between the women accessing services in the clinic and the members of staff.

Despite all of the measures used to facilitate an optimum recruitment, antenatal recruitment was very poor. A meeting was held with the members of staff who facilitated the clinic to ascertain whether further training was required for members of staff in order to discuss the study with potential participants with the remit of inviting women to take part in the study. The universal conclusion of the meeting was that despite previous meetings to discuss the study, the health care professionals felt that it was inappropriate to invite women to take part in any research regarding FGM due to the perceived vulnerability of the women; this was despite a rigorous ethical approvals process. Equally, the recruitment of women from the antenatal clinic that is provided in parallel to the FGM clinic was very poor. There was only one woman who was recruited antenatally who took part in the interview postnatally as described; this woman was recruited from a consultant midwife clinic, not the FGM clinic or antenatal clinic.

Due to the difficulties in recruitment of antenatal women, the study invitation letter and participant information sheets were distributed to the postnatal wards. Following the discussion with the ethics committee at the planning stage, the panel believed that recruitment postnatally would generate participant recruitment that may not be possible antenatally due to FGM survivors not being identified prior to labour care. Although it was perceived that recruitment would be poor from the postnatal wards due to low staffing levels and high workload, the staff successfully facilitated recruitment. As a result, the majority of participants were recruited from the postnatal wards. The postnatal floor had a frequent placement of student midwives who appeared to have a greater FGM awareness than the midwives. The seconded specialist FGM midwife

provided FGM awareness training at the university where the student midwives completed the academic aspect of their training. As a result, midwifery students had a more comprehensive cultural awareness of FGM than the midwifery staff.

Only two women revisited the hospital following postnatal discharge in order to take part in the interviews, but the majority of women were interviewed immediately following their discharge from the wards; this added to their convenience since the women were still in the hospital building at this time.

Further problems that were anticipated did occur; some midwives were unable to identify potential participants due to insufficient training in identification. I had previously developed education packages for midwives and obstetric doctors and continued to deliver awareness training to the public health and social care teams in the university setting. I had also previously delivered half day workshops to student midwives at the University, which has become embedded in the curriculum, so that on graduation midwives already had a basic awareness of FGM women. However, this became part of an unanticipated problem.

Reflection was required on this unanticipated problem; my preclusion from the FGM services and training at the research site. As a midwife who was employed at the research site within the Governance Team, the belief of the maternity management team was that I did not have the pre-requisite clinical experience to work within the

clinical area with FGM survivors and that my knowledge on FGM was purely academic. This was despite me having worked as a clinical midwife for seven years in other NHS Trusts prior to joining the Governance Team at the research site and working with FGM survivors as part of my role. This became a challenging problem due to not having access to the FGM service or being able to implement any training at the research site. Midwives were signposted to the online training that was discussed in section 4.6 which is focused predominately on outsider opinions and the legal aspects of care. As a result, the midwives at the research site had limited knowledge of FGM which in turn fostered the perceived vulnerability of women who had experienced FGM; this was identified during the data gathering period and may explain the poor antenatal recruitment.

A further anticipated problem that may have occurred was when women who had indicated that they were willing to participate in the study but had been discharged home from the hospital prior to the consent procedure being discussed and accepted. However, this problem did not occur. A record of women who had agreed to take part in the study during their antenatal period was maintained in an attempt to avoid this potential problem, however only two women were recorded due to poor antenatal recruitment; only one woman participated. Nevertheless, this record was kept in the same locked cupboard within a locked office at the research site; this was stored in the same location as the data that was collected. No individual other than me at the research site had access to this information.

Further limitations occurred as a result of little support from the research site. Prior to ethical approval, the study was discussed with the head of service at the research site; this included the aims and the perceived outcomes of the study. However, the study, as well as the perceived outcomes from the research, were considered to be insignificant and 'merely an academic exercise' due to the research being an element of a PhD programme. Although permission was granted to access potential participants, as well as to conduct qualitative interviews, there was no support from the research site for the research or the researcher. This was a significant concern due to being an employee at the research site at the time of the research. Ultimately, these issues were a potential risk to the continuation of the research. On reflection, the identification of these risks was crucial and enabled me to reflect on mitigating actions to ensure that the research could continue. As a result, and to alleviate any potential or actual risk, all work relating to the research and PhD programme was carried out outside of the hours of employment.

9.5 Reflection on the sound of silence framework

This section presents the researcher reflection on the sound of silence framework. The framework used for reflection is based on the CARL (Context, Action, Result, Learning) framework (University of Edinburgh, 2018). Furthermore, in view of this section being a reflection by the researcher, this is presented in the first person.

9.5.1. Context

At the beginning of my journey with this study, I believed that FGM survivors were a particularly vulnerable group of society and survivors accessing maternity services

were therefore one of the most vulnerable and marginalised populations who would access maternity services. Whilst I had already spent a number of years providing awareness training to health care professionals and clinical care to FGM survivors, I had questions that I was unable to find answers to. Care for FGM survivors became more prescribed through statute and when providing this care to survivors, I felt embarrassed to ask questions of their family, their intentions towards their daughters or their beliefs around FGM. Whilst these changes to care provision took place, I noticed that there was an absence of FGM survivors' opinions within the guidelines and wondered why this was the case. I assumed that FGM survivors were silent due to cultural differences, that FGM was a taboo subject or were marginalised due to their beliefs around FGM. Therefore when I discovered the silences framework for conducting research with groups who are perceived as silent, this resonated with me. Serrant-Green (2011) explained that the silences framework was developed with 'broader theoretical theories' which consisted of criticalism, anti-essentialism and feminism which appeared to be key components of my study. As a result, I adopted the silences framework to underpin my research.

9.5.2. Action

When reviewing the structure of the silences framework, I believed there was opportunity to provide FGM survivors with a platform to voice their experiences of maternity care, as well as health care professionals being able to respond to such voices. However, when formulating the structure of my study, I realised that voices in the findings from initial FGM survivors' interviews may be further silenced by the health care professionals who were in a position to challenge FGM voices and opinions. As a result, I modified the phases of analysis in stage three so that FGM survivors were

the final participant voices who were able to respond to the health care professionals' views and opinions. However, for me, this did not alleviate the problem.

9.5.3. Results

I acknowledge that I, as a midwife, was an insider to the health care professionals but an outsider to FGM survivors. I had spent a number of years providing awareness training to health care professionals, as well as wider audiences such as social care and academics, so potentially I was already aware of their views and opinions. However, the silences framework had given me a platform to express my identity and position in this study and the potential for subjectivity to be introduced into the construction, as well as the findings, of the research as a result of my background. This led me to ask further questions; of myself and of the silences framework. These consisted of:

- *What is 'the sound of silence'?*
- *Can we 'hear' silence?*
- *What is 'a silence'?*
- *Who is silenced?*
- *Why is someone silenced?*
- *Who is a silencer?*
- *Am I a silencer?*
- *Do I have pre-conceived answers to this study?*
- *Am I trying to prove silence?*
- *How do I create a dialogue from 'silence'?*

I realised that these questions were around the word 'silence' which then impacted on my perspective of the silences framework. I realised that 'silence' is a powerful word and I felt that claiming that someone is 'silenced' introduced significant power into a relationship. I then considered the use of the term 'voice' in the context of the

framework and how, as a researcher, I would be ‘voicing silences’. This expression generated feelings of discomfort with me; I already felt that power was introduced into the silences framework with the claim that a person or group of people (and/or their experiences) were silenced by someone (or something). This became a challenge due to power already existing within the FGM survivor-health care professional relationship. But to claim that I was giving participants a ‘voice’ from the findings implied an even greater power imbalance. I then began to ask myself further questions:

- *Am I lending people my voice?*
- *Are they lending me their voice?*
- *Am I giving them a voice?*
- *Am I labelling the participants as ‘voiceless’?*
- *Surely the ‘voiceless’ already have a voice?*
- *How can I voice someone else’s views and beliefs if these are different to mine?*
- *Has the silences framework situated me in a position of power?*
- *Is the silences framework introducing more power while I am trying to rebalance this?*

Whilst the silences framework claims that the ‘listener’ or the researcher is the primary vehicle who hears the ‘silence’ and ‘voices’ the silence, it cannot be ignored that the ‘vehicle’ is a subjective person. As a result, using such terms can risk dehumanisation and allude to objectivity when hearing and voicing ‘silences’. Despite the platform for reflection on researcher position and identity, the issue of researcher ‘power’ persisted. For example, while I attempted to directly use the data from the FGM survivors’ interviews to construct the discussion guide for health care professional focus group, I was the individual who analysed the data and therefore generated the themes. This led me to question whether the silences framework is suitable for researching sensitive subjects with groups who are outside of the researcher’s cultural and/or social background. However, discourse analysis was instrumental in uncovering silences in health care professional as well as FGM survivors.

9.5.4. Wider learning

At the beginning of this study I believed that I had accumulated a considerable amount of knowledge of FGM which enabled me to commence this research. I believed that I understood the topic comprehensively and equally understood the practice and its implications for women. I believed that FGM was a sensitive topic which was difficult for FGM survivors to discuss. But on this journey, I have learned more about FGM than I could have imagined. I have learned that FGM survivors do want to discuss their experiences; it appears that western society is not adept at hearing those experiences due to the power, vulnerability and agency introduced into FGM by (Hosken, 1979a) second-wave feminist interpretation. I have also learned that FGM is not just an act or procedure, FGM is a feeling and/or a belief which is personal to each woman that has experienced it. I have learned that we use FGM as a label without asking that person if they 'feel' or 'believe' they have been mutilated. I have learned that we have only just begun to attempt to understand FGM and the effect on those who have experienced it. While there is a growing body of FGM 'experts' in the UK I have realised, at the end of this study, that the only true experts of FGM are the women who have survived and live with FGM every day of their lives.

9.6 Recommendations

The findings from this study suggest that cultural sensitivity is silent in maternity services provided to FGM survivors. Equally, it appears that the knowledge and education of health care professionals can have an impact on the care FGM survivors experience in maternity services but it also seems to affect the way health care professionals provide care. For instance, the way services are monitored and regulated appear to prevent health care professionals from providing culturally

responsive care and as such was interpreted as silent in this study. In parallel, there appears to be a lack of cultural sensitivity in clinical guidelines due to the inclusion of legal implications in guideline recommendations. It seems that this leads to culturally insensitive care experiences for FGM survivors accessing maternity services. Furthermore, mental health services for FGM survivors are not seamless in maternity services which appears to be linked to a lack of understanding of the relationship between mental health issues and FGM. In view of these findings, the following sections consist of recommendations to address the suggested issues interpreted from this study.

9.6.1. Communication

Communication between FGM survivors and health care professionals in maternity services was an overarching themes interpreted during this study. It appears that communication also relates to each of the other overarching themes as well as the silences interpreted in this study. The literature review uncovered that clinical guidelines and educations are constructed by, and utilising the views and opinions of, outsiders of the people who have experienced FGM. Although the UK government took the important step of introducing FGM survivors' voices into government initiatives, such as the Home Affairs committee discussions on FGM (Moore et al., 2016), more can be done.

The first step is to form collaborative working groups with key stakeholders to help improve communication, as well as improve the guidance and education on communication with FGM survivors. The inclusion of FGM survivors in such groups is

an important step in ensuring culturally informed opinions are included in health care professional education packages but also in clinical guidance.

Figure 16: Working group to provide expertise on FGM

Figure 16 represents an illustration of the recommended key stakeholders for such working groups. However, the length of membership of a group is an important consideration since there is potential for a small group of opinions to be integrated into mainstream health care professional education and clinical guidance. Therefore, it is recommended that membership of a working group is limited to three years. The benefit of revising the working group membership at three years is so that each new group has the opportunity to review the clinical guidance in comparison to evidence (and new evidence that may have emerged) as well as review education that is available for health care professionals.

9.6.2. Service provision

The way services are provided to FGM survivors appeared to have an impact on the care experienced. For instance, there was evidence that FGM survivors had no information or understanding regarding referrals to other services such as an FGM clinic. It seemed that clinical guidelines were a catalyst in this finding and appeared to be the root of the dominant discourses that were interpreted in this study. One of the issues that was reported was the inclusion of legal aspects of FGM, which are present as recommendations in clinical guidance. The recommendation to discuss legal aspects in a health care setting seemed to be a factor in the interpretation of cultural insensitivity of FGM survivors in maternity care. This section presents the recommendations for service provision and clinical guidance that have arisen from the findings of this study.

Firstly, in relation to the scoping of new guidelines, as well as the review and revision of existing guidelines, it is recommended that guideline development is one of the central responsibilities of the working groups that are recommended in section 9.6.1. These working groups will provide a different perspective of care for FGM survivors, which may improve the experience of care as well as the experience of providing care.

Secondly it is recommended that the discussions of legal implications be removed from clinical guidelines. Whilst it is important for health care professionals to have a working knowledge of the legal aspects of FGM (as well as implications for their practice), including such messages as measurable standards appears to be inappropriate. It seems that the outcome of care experiences and the relationship with health care

professionals, as well as the discourse between them and FGM survivors, is affected by these conversations. Equally, it suggests that health care professionals are providing judgmental care in that they appear to be labelling FGM survivors as victims or perpetrators. This was interpreted from the data collected from FGM survivors who described health care professionals as “only caring about the law” (FS19). In a clinical situation where trust in a health care professional is crucial to outcome, introducing legal conversations might inhibit or damage that trust. Removing the legal implication of FGM from clinical guidance may contribute to health care professionals’ ability to provide culturally responsive and culturally sensitive care and significantly improve the experience of maternity care for FGM survivors.

9.6.3. Knowledge and education

In parallel with communication and service provision, the knowledge and education that health care professionals had of FGM appeared to impact on the maternity care that FGM survivors experienced as well as the experience of providing care. This was acknowledged by both the FGM survivors and health care professionals. Furthermore, the health care professionals suggested that FGM awareness training was inadequate and FGM survivors suggested that health care professionals seemed to focus on the illegalities of FGM as well as safeguarding triggers.

NHS England, in collaboration with the Department of Health and Royal Colleges, implemented an FGM Prevention Programme which aimed to ‘care, protect and prevent’ in relation to women living with FGM. However, these sentiments appear to have been limited to experimental data collection to map the prevalence of FGM across

England and Wales. Although Health Education England (Reisel et al., 2016) and the Home Office (HM Government, 2016) have developed education packages to raise awareness of FGM, a critical review of these suggested that cultural sensitivity was absent. In fact, the Home Office training package stated that cultural sensitivity should not get in the way. This suggests an ethnic absolutism approach to education with a generalisation regarding the victim-perpetrator agency directed at FGM survivors themselves. The findings from the health care professional focus group appeared to corroborate this; particularly with reference to women being “scared to talk about FGM” (HCP02) and the need to refer women to safeguarding services (HCP09). As such, there needs to be a change in the education of health care professionals to improve the knowledge and understanding of FGM in this sector.

Firstly, it is recommended that education is developed by working groups that were outlined in section 9.6.1. The multi-professional and multi-agency collaboration, in conjunction with patients and public, will provide broader perspectives to health care professionals in education. Secondly, whilst there appears to be an attempt at inquiry-based learning in current e-learning packages, there needs to be a shift away from using safeguarding and legal aspects in the inquiry-based learning section of the education programmes. Whilst these are important aspects of education and knowledge for health care professionals, there is risk that the safeguarding and legal implications become more important than culturally responsive and culturally sensitive care. As such, it is recommended that the inquiry-based learning elements of education consist of the cultural aspects of FGM and the safeguarding and legal aspects are provided on an information-based level within the programmes.

9.6.4. Mental health care and FGM Survivors

The provision of mental health care for FGM survivors was an important finding. It suggests that mental health care for FGM survivors is not seamless in maternity services. This was evident in the findings from both the FGM survivors and the health care professionals. For instance, one FGM survivor had already received a diagnosis for a mental health concern but was referred to their GP regardless; some health care professionals corroborated this by stating that clinical guidelines recommend referral to GPs for FGM survivors who report, or appear to experience, mental health concerns.

FGM services and mental health services for pregnant women both exist under the umbrella of vulnerable women services, yet both appear to be compartmentalised with no collaboration between the two services. As such, since there is already potential for the collaboration between the two services it is recommended that pathways are developed to provide mental health care within maternity services for FGM survivors which will achieve a seamless provision of maternity care. Furthermore, this will achieve continuity of care rather than disjoining such care and isolating FGM survivors to mental health services external to maternity care. Figure 17 presents a SWOT[28] analysis of implementing collaborative care of FGM survivors in maternity mental health services.

[28] A SWOT analysis consists of the **S**trengths, **W**eaknesses, **O**pportunities and **T**hreats of implementing the service

Figure 17: SWOT analysis of FGM and Mental Health collaboration in Maternity services

Whilst the strengths and opportunities of this SWOT analysis relate to the recommendations presented herein, the weaknesses and threats are acknowledged which might impede operationalising these findings into clinical practice. Therefore comprehensive planning of operationalising such services is recommended. Figure 18 presents a suggested method and steps for operationalising this recommendation in practice.

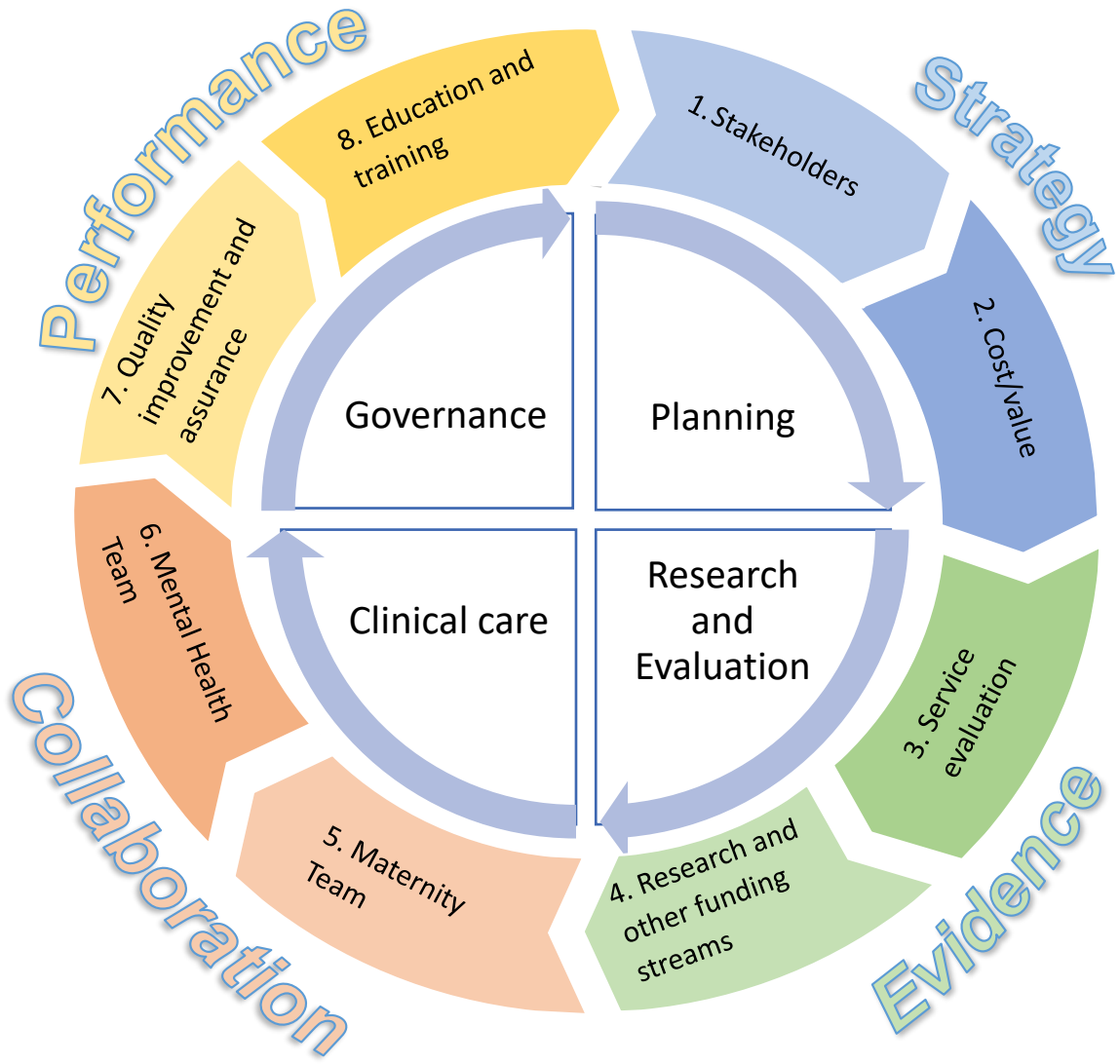

Figure 18: Recommendations for operationalising mental health care for FGM survivors in maternity services

(i) Strategy

Establishing a robust strategy is the first, and most important, step in implementing a change to clinical practice, regardless of the size or manner of the change. The involvement of key stakeholders in this change is vital in ensuring that the proposed

service is effective in meeting the needs of those who will benefit. As such, the key stakeholders included in the strategic planning should include, but not limited to, workforce and operational development teams, service user representatives, governance teams across the collaboration, those who are responsible for each service (such as heads of department) and representatives from the point of care (such as clinicians). Furthermore, to demonstrate cost-effectiveness of developing such a strategy will require representatives from finance departments to demonstrate financial planning is incorporated into the strategic plan.

(ii) Evidence

Presenting evidence for change is key in developing and/or redeveloping services. Although there are suggestions in this study for the reasons for this collaboration of services, it is recommended that local services are evaluated to determine the existing service structures, the existing local delivery of services, the cost and safety effectiveness and the benefit to service users and practitioners of collaborating services. It is therefore recommended that a SWOT analysis is carried out locally to determine these factors.

Funding of such services may be a barrier to local service development. Therefore incorporating external funding opportunities under the 'evidence' umbrella of operationalising services may be beneficial. Such funding opportunities can be accessed through research or commissioned service developments (such as NHS England's commissioning for quality and innovation (CQUIN) programme). Furthermore, whilst initial evidence is vital to providing the rationale for service

development and/or redevelopment, continually generating evidence in the form of research and service evaluation can present important opportunities for continuing external funding as well as evidence to continually improve services. Therefore, it is recommended that an evidence stream is embedded within a strategic plan since this is strongly associated with financial planning as well as governance streams. Equally, it provides opportunities for the collaboration of services from both a governance perspective and funding perspective.

(iii) Collaboration

The collaboration of services is central to the recommended strategic plan which itself presents challenges. Whilst it may not be operationally and financially feasible to create a new role that would encompass a holistic practitioner of FGM and mental health specialisms, there is opportunity to provide an aspect of knowledge to practitioners who specialise in each field. For instance, FGM specialist practitioners should be provided with opportunities to gain knowledge and understanding of mental health issues in FGM survivors which presents a trigger to refer these women to the maternal mental health practitioner and vice versa. In doing so, the care remains seamless in maternity services. However, there is a risk that FGM survivors may be subjected to multiple appointments within the same service. As such it is also recommended that joint clinics are held for FGM services and mental health services to capture women who may not have the means (or ability) to attend multiple appointments. Even so, this may present challenges in terms of environmental resource. Hence it is recommended that alternate clinics are held in collaboration so that services are streamlined into one clinical area.

(iv) Performance

Integral to service development/redevelopment is a performance measurement workstream which is central to the monitoring and assurance of the service. Therefore, incorporating a performance plan is an important feature of operationalising a service improvement. However, it is suggested that the recommendations in guideline redevelopment (presented in section 9.6.2) are implemented prior to the development of quality assuring services in the form of clinical audits due to the risk of measuring the performance of legal discussions.

Education and training is a key feature of performance and is integral to the governance of a proposed service development/redevelopment. Ludlow and Armstrong (2016) suggest that learning together presents opportunities for peer learning and supports an inquiry-based learning approach. Furthermore, this approach incorporates a range of pedagogical approaches such as social, critical and socratic pedagogy. Equally, since the findings of this study around cultural sensitivity and improving culturally responsive care can be incorporated into such learning which may meet culturally responsive pedagogical needs.

9.6.5. Further research

This study has uncovered silences amongst health care professionals around FGM which has led to further unanswered questions. Whilst other recommendations relate to clinical guidance, service provision and education, the recommendations in this section relate to further research that may help to answer these questions.

This study was a small-scale, single centre study which interpreted silences around the maternity care of FGM survivors. However, there may be further silences that have not been heard in this study. In view of this, it is recommended that a large-scale, multi-centre study is conducted to explore the experiences of FGM survivors maternity care and the experiences of health care professionals in providing such care. This should include areas where FGM has been identified in areas of high and low prevalence to map the care that is provided to FGM survivors as well as the education of health care professionals across the UK.

The perinatal mental health of FGM survivors would benefit from further research. In particular, to ascertain the understanding and impact of mental health care concerns amongst FGM survivors. Furthermore, evaluation of services provided to FGM survivors in maternity services may uncover further gaps in maternity care for FGM survivors. Hence a further recommendation for maternity services is to include FGM services to the annual national maternity and perinatal (NMPA) audit, which is commissioned by the RCOG, to ascertain the quality of care across NHS maternity services. Included in the NMPA audit scope is a programme of flexible, periodic audits which are collectively termed as sprint audits (RCOG, 2019). It is recommended that FGM services within maternity services are audited as part of a sprint audit to ascertain the quality of care provided to FGM survivors. This might provide some insight into the areas of mental health care that could be improved for FGM survivors.

Whilst this study uncovered a disjoint around FGM survivor's maternity care and mental health care, it did not uncover the true extent of mental health issues in FGM

survivors who access maternity care. Furthermore, it did not ascertain whether services for FGM survivors improve or worsen mental health illness in these women. Therefore, to answer these important questions, it is recommended that a study of perinatal mental health of FGM survivors is conducted to understand the extent of mental health illness of these women accessing maternity care. This should include FGM survivor's mental health status on initial access to maternity services, the care provided and the outcomes of their maternity care and whether their mental health has improved or worsened. Furthermore, and to explore health care professionals perspectives of mental health care of FGM survivors, it would be useful to include various health care professionals in such a study. These should include (but not limited to) midwives, obstetricians, GPs, psychologists and mental health nurses.

9.7 Chapter summary

This chapter has presented the new knowledge that has resulted from the findings of this research; these consisted of cultural silences model to determine whether silence exists in health care-patient relationships, the implications and wider context of maternity care for FGM survivors and opportunities for improving education and guidance for health care professionals. In addition, this chapter has presented the outcome of applying the silences framework to research in maternity services which included a researcher reflection on its use.

Furthermore, this chapter has presented the rigour of this study and how the methods of this study can be applied to other areas for use. This chapter has concluded the thesis with a presentation of the recommendations that have emerged as a result of this research.

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Appendix I

Invitation to participate

Dear …….

I am writing to invite you to participate in a research project, which I am conducting as part of a PhD programme at the University of Wolverhampton. I enclose an information sheet, which explains the title and aims of the project and what taking part will involve.

If you are willing to be interviewed, the interview would take between 30 and 45 minutes. Anything you say would be totally confidential and any notes made as a result of the interview would be destroyed afterwards. The interview would take place in the postnatal department of Birmingham Women's Hospital at a convenient time while you are on the postnatal ward. Alternatively, you may return to the hospital at a time of your choosing. A report will be written of the findings and numbers will replace all names so that you cannot be identified. I would also welcome you to discuss the general thoughts and feelings that emerge from the findings. All information will remain strictly confidential.

If you feel that you would like to take part, please inform your community midwife or antenatal clinic midwife at your next visit. If you would prefer not to be involved, please destroy/ignore this letter. If you decide not to be involved I would like to assure you that your care will not be affected in any way.

Yours sincerely,

Emma Danks

السيدة ..... المحترمة

أكتب إليكِ لأدعوك للمشاركة في مشروع البحث العلمي الذي أقوم به كجزء من رسالة الدكتوراة في جامعة وولفرهامبتون. مرفق مع هذه الرسالة ورقة معلومات تشرح العنوان والهدف من هذا المشروع وما تتضمنه المشاركة فيه

إذا كنت لا تمانع في مقابلة يستغرق ما بين 30 إلى 45 دقيقة. كل ما تقوله وسوف تظل سرية وسيتم تدمير كافة الملاحظات في هذه المقابلة بعد ذلك. سوف تجري المقابلة في جناح الولادة في مستشفى "النساء في برمنغهام"، أو في وقت لك. سيتم كتابة تقرير حول المقابلة وسيتم استبدال رقم الاسم الخاص بك للتعرف عليك. وأرحب أيضا مناقشة أي أفكار أو مشاعر نتيجة ذات الصلة من هذه المقابلة، وجميع هذه المعلومات ستبقى سرية.إذا كنت ترغبين بالمشاركة الرجاء وضع علامة على الورقة المرفقة وإعطائها للقابلة في البيت أو في العيادة لدى زيارتك القادمة. أما إذا كنت لا ترغبين في المشاركة فرجاء إهمال هذه الورقة. في حال قرّرتِ عدم المشاركة فأُؤكد لك أن الرعاية الصحية المقدمة لك لن تتأثر بأي شكل.

ولكِ جزيل الشكر

إيما دانكس

Cher……

Je vous écris pour vous inviter à participer à un projet de recherche, qui je effectue dans le cadre d'un programme de doctorat à l'Université de Wolverhampton. Je joins une feuille d'information, ce qui explique le titre et les objectifs du projet et quelle partie prise impliquera.

Si vous êtes prêt à être interviewé, l'entrevue prendrait entre 30 et 45 minutes. Tout ce que vous dites serait totalement confidentielles et des notes prises à la suite de l'entrevue serait détruit par la suite. L'entrevue aura lieu dans le département après la naissance Hospital de Birmingham Womens à un moment opportun pendant que vous êtes dans la salle postnatale. Alternativement, vous pouvez retourner à l'hôpital à une heure de votre choix. Ce sera à un moment qui est commode pour vous. Un rapport sera rédigé des conclusions et des numéros remplacera tous les noms de sorte que vous ne pouvez pas être identifié. Je voudrais également vous accueillir pour discuter les idées générales et les sentiments qui se dégagent des conclusions. Toutes les informations resteront strictement confidentielles.

Si vous sentez que vous souhaitez participer, se il vous plaît indiquer sur la feuille ci-jointe et remettre la lettre à votre sage-femme de la communauté ou de la clinique prénatale sage-femme lors de votre prochaine visite. Si vous préférez ne pas être impliqué, se il vous plaît détruire / ignorer cette lettre. Si vous décidez de ne pas participer, je voudrais vous assurer que vos soins ne sera pas affecté en aucune façon.

Sincère,

Appendix II

Participant Information Sheets

Participant Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, / relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Study title

A qualitative retrospective study of the experiences of women who live with female genital mutilation accessing maternity services in the UK

What does the title mean?

The study is asking postnatal women, who have experienced female circumcision/genital cutting at some point during their life, about their care with doctors and midwives. This means the care you receive from initially meeting your community midwife, until you have had your baby and have gone home.

What is the purpose of the study?

The study is being carried out as part of a Doctor of Philosophy (PhD) degree through the University of Wolverhampton. A PhD is a university degree which involves carrying out research as part of the whole project. The person carrying out the research is Emma Danks who is the midwife responsible for audit, guidelines and patient experience at Birmingham Women's Hospital. The purpose of the research study is to investigate how women who have experienced FGM/C felt about the care they received during pregnancy, labour and postnatally. Further aims of the study are to understand whether women believe that health care professionals have a cultural understanding of FGM/C and if their needs have been met from a cultural, emotional and physical aspect by midwives and doctors.

The study will take approximately 3 years to complete in total, but each woman's involvement in the study will be for one interview which will last between 30 and 45 minutes.

Why have I been invited to take part in this study?

You have been invited to take part in this study because you have been identified to have experienced FGM/C at some point during your lifetime.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. As part of the consent form, we will ask whether we can look at your medical records. This will give us a clear idea of how you have been cared for before, during your pregnancy and after you have had your baby. Your records will not be looked at before you agree to this by signing the consent form. If you decide to take part you are still free to withdraw at any time[29] and without giving a reason. Be assured that if you decide not to take part, this will not affect the standard of care that you receive.

What will happen if I decide to take part?

Although the research will take approximately 3 years to complete, your participation will be for the 30 – 45 minute interview and 30 – 45 minute discussion to discuss the findings at a later date (if you choose to do so). During the interview, you will be asked about your experiences of the care you have received during your pregnancy, labour and after you have had your baby. The interview will take place in a secure room with no interruptions from any other person. For your added security, the door to the interview room can be locked if you wish. The interview will be recorded onto a digital recording device which will be kept in a secure office inside a locked cupboard so that no one has any access to your interview.

You are welcome to participate in the interview before you are discharged home from the postnatal ward, but if you chose to return to the hospital to participate in the interview, the researcher will reimburse your travel expenses. Please discuss this with the researcher before you decide to take part.

What are the potential benefits and risks of taking part?

Though there are no direct benefits for you if you take part, but by taking part you will help us to have a deeper understanding of the cultural ideas about FGM/C. This may help us to improve the way women who have experienced FGM/C are cared for in the future.

There are no risks to you in taking part in this study. However, by taking part, you may remember things that you may find upsetting. If this occurs, the researcher will ask you if you want to continue to participate in the interview. Any decision you make will be respected.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The recordings and transcription of the interview you participate in will be stored on a password protected computer in a locked cupboard within a locked office. Only the researchers working on the project will have access to any of this information. You will not be identifiable in any

publication or report as the data will be grouped together and all identifying information will be removed.

When all of the data has been collected together and the research has been published, all of the recordings and transcriptions of interviews will be destroyed. This will be a maximum of two years after the research has been completed.

However, if anything is raised during the interview that indicates that either you or someone else is at risk of harm, then these concerns will have to be taken further. If there is an indication that you or someone else is at risk of significant harm then it is the duty of the researcher to share this information with the Police and local safeguarding adult and children's teams. Equally, if FGM/C has occurred in the UK, it is the duty of the researcher to inform your local safeguarding children's organisation and the police.

What will happen at the end of the research study?

The findings of the research will be published widely. However, no one will be able to identify you or anyone else that takes part in the research as all data will be anonymized. I will also provide you with a summary copy of the findings in a format that is easy to understand so that you have the opportunity to keep a copy for yourself.

What if I have a problem or concern?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions. Alternatively, if you have any concerns about the way any questions have been asked or any other concerns that you do not wish to discuss with the researcher directly, you may contact the researcher's supervisors on:

Dr Angela Morgan

[redacted]

[redacted]

Dr Ranjit Khutan

[redacted]

[redacted]

If you would like to discuss participation in this study with someone at the hospital who is not involved with the study, please contact [redacted] (Consultant Midwife) who is a Supervisor of Midwives and will be happy to discuss any concerns that you have. You can contact [redacted] on:

[redacted] or telephone the switchboard on [redacted] and ask to be put through to [redacted].

Who has reviewed the study?

This study has been reviewed by the Research Ethics Committee of the University of Wolverhampton and the Ethics Committee that reviews research prior to studies being carried out at the hospital.

Contact for further information

If you would like any further information regarding the study, please do not hesitate to contact me on:

[redacted]

[redacted]

I would like to take this opportunity to thank you for your interest in this study.

Version Number: 3 Date: 7th July 2016

Further Support

This study may bring back some memories that are upsetting, painful and/or unpleasant. The research supervisory team and I have included the list of contacts below of organisations that can talk through any fears and painful/upsetting memories. All of these contacts are skilled with helping women who have experienced FGM/C.

Acton African Well Women Centre, Acton Health Centre	35-61 Church Road Acton, West London, W3 8QE	020 8383 8761 020 8383 8712
African Women's Clinic, University College Hospital	Clinic 3, Elizabeth Garrett Anderson Wing, NW1 2BU	0845 155 5000 ext. 2531
African Women's Clinic Women & Health	4 Carol Street Camden, London, NW1 OHU	0207 482 2786
African Well Women's Clinic, Guy's and St Thomas' Hospital	8th Floor – c/o Antenatal Clinic, Lambeth Palace Road, London SE1 7EH	020 7188 6872 07956 542 576
African Well Women's Clinic, Whittington Hospital	Level 5 Highgate Hill, London N19 5NF	020 7288 3482 ext. 5954 079566257992
Birmingham and Solihull Women's Aid	44 – 48 Bristol Street, Birmingham, B5 7AA	0121 685 8687 0808 800 0028 (Freephone from landline and most mobile numbers)
African Well Women's Clinic, Central Middlesex Hospital	Antenatal Clinic, Acton Lane, London, NW10 7NS	020 8963 7177 020 8965 5733
Woodfield Medical Centre Antenatal Clinic	7e Woodfield Road, W9 3XZ	020 7266 8822

Women's and Young People's Services, Sylvia Pankhurst Health Centre, Mile End Hospital	3rd Floor, Bancroft Road, London, E1 4DG	020 7377 7870 020 7377 7898 020 8223 8322
West London African Women's Hospital Clinic	Gyanecology and Antenatal Clinics, Chelsea and Westminster Hospital, 369 Fulham Road, SW10 9NH	020 3315 3344
Nottingham University Hospitals, City Campus, Labour Ward	Hucknall Road Nottingham, NG5 1PB	0115 969 1169 ext. 55124
Multi-Cultural Antenatal Clinic Liverpool Women's Hospital	Crown Street Liverpool, L8 7SS	0151 702 4085
Minority Ethnic Women's and Girls Clinic, Charlotte Keel Health Centre	Seymour Road Easton, Bristol BS5 0UA	0117 902 7111 (direct line) 0117 902 7100 (switchboard)
Birmingham Heartlands Hospital, Princess of Wales Women's Unit, Labour Ward	Bordesley Green East Birmingham B9 5SS	0121 424 0730

نشرة معلومات للمشاركات في البحث

لقد تمّت دعوتكِ للمشاركة في بحثٍ علميٍ. قبل أن تقرري المشاركة أو عدمها فإنه من الضروري أن تعرفي لماذا نقوم بهذا البحث وماذا يتضمن. أرجو أن تأخذي الوقت الكافي لقراءة نشرة المعلومات هذه ومناقشتها مع أصدقائك أو أقاربك إذا أردت ذلك. لا تترددي في سؤالنا إذا كان هناك شيءُ ما غير واضح أو إذا أردتِ معلوماتٍ أكثر. شكراً للقراءة

عنوان الدراسة

دراسة نوعية بأثر رجعي عن تجربة النساء اللائي خضعن للختان مع الخدمات الطبية للحوامل في المملكة المتحدة

ما الذي يعنيه هذا العنوان؟

ويتم تنفيذ هذه الدراسة كجزء من دكتور في الفلسفة)دكتوراه (درجة من خلال جامعة ولفرهامبتون .درجة .الدكتوراه هو الحصول على شهادة جامعية الذي ينطوي على إجراء البحوث كجزء من المشروع بأكمله عند الذي هو القابلة المسؤولة عن التدقيق والمبادئ التوجيهية Danks الشخص تنفيذ هذا البحث هو إيما .وتجربة المريض في مستشفى برمنغهام المرأة

بعد الولادة تسأل الدراسة النساء اللائي خضعن للختان في أي مرحلة من حياتهن عن الرعاية الطبية التي تلقينها من الأطباء والقابلات. هذا يتضمن الرعاية منذ اللقاء الأولي مع القابلة في المجتمع وحتى الولادة والذهاب للبيت

ما هي الغاية مع هذه الدراسة؟

نقوم بإجراء هذا البحث العلمي لمعرفة كيف تشعر النساء اللائي تعرضن للختان اتجاه الرعاية الطبية خلال الحمل والولادة والنفاس. من الأهداف الأخرى لهذه الدراسة معرفة ما إذا كانت النساء المختونات تعتقدن بأن مقدمي الرعاية الصحية لديهم الوعي الكافي عن ختان النساء وما إذا كانت حاجاتهن الحضارية والعاطفية قد تم الاستجابة لها من قبل الأطباء و القابلات.

تستغرق هذه الدراسة حوالي الثلاث سنوات لتكتمل ولكن مشاركة كل إمرأة فيها لا تستغرق سوى مقابلة واحدة لمدة 30 إلى 45 دقيقة.

لماذا أنا تم اختيار المدعوين للمشاركة في هذه الدراسة؟

تم اختيارك للمشاركة في هذه الدراسة لأنك خضعت للختان في مرحلة ما من حياتك

هل تجب علي المشاركة؟

قرار المشاركة في هذا البحث يعود كلياً إليكِ. إذا قررت المشاركة سنعطيك ورقة المعلومات هذه ونطلب منك التوقيع على استمارة موافقة على المشاركة. وحتى إذا قررت المشاركة فبإمكانك الانسحاب في إي وقت تشائين بدون إعطاء أي سبب. وإذا قررت عدم المشاركة فالعناية الصحية المقدمة إليكِ لن تتأثر.

كجزء من استمارة الموافقة، ونحن سوف نسأل ما إذا كان يمكننا أن ننظر في السجلات الطبية الخاصة .
.بك .وهذا يعطينا فكرة واضحة عن الكيفية التي تم العناية بها قبل وأثناء الحمل وبعد أن كنت قد كان طفلك
.لن يتم النظر في السجلات الخاصة بك قبل أن توافق على هذا من خلال التوقيع على استمارة الموافقة

ماذا يحصل إذا قررت المشاركة؟

على الرغم من أن الدراسة تستغرق حوالي الثلاث سنوات لتكتمل إلا أن مشاركتك تنحصر على 30-45 دقيقة مقابلة وربما 30-45 دقيقة أخرى لمناقشة النتائج في وقت لاحق (إذا شئتِ). خلال المقابلة سيتم سؤالك عن تجربتك مع الرعاية الصحية التي تلقيتها خلال الحمل والولادة والنفاس. تتم المقابلة في غرفة آمنة بدون إزعاج من أي شخص وسيتم تسجيل المقابلة على شريط يبقى في مكان آمن في خزانة مقفلة.

أنتم مدعوون للمشاركة في مقابلة قبل أن يتم تفريغها المنزل من عنبر ما بعد الولادة، ولكن إذا اخترت العودة إلى المستشفى للمشاركة في المقابلة، فإن الباحث تسدد نفقات السفر .يرجى مناقشة هذا الأمر مع .الباحث قبل أن تقرر المشاركة

ما هي الفوائد المرجوة والمخاطر المحتملة من المشاركة؟

على الرغم من أنه لا توجد منفعة مباشرة لك من المشاركة، إلا أن مشاركتك ستساعدننا على فهم الجانب الحضاري لختان النساء مما قد يساعدنا في تطوير الرعاية الطبية للنساء المختونات

لا يوجد أي مخاطر من الاشتراك في هذه الدراسة ولكن المشاركة قد تذكرك بأمور ممكن أن تجديها مزعجة. وفي هذه الحالة ستسألك الباحثة عما إذا أردت الاستمرار في المقابلة أم لا وسيتم احترام أي قرار تتخذينه

هل ستبقى مشاركتي في هذه الدراسية سرية؟

نعم. ستبقى جميع المعلومات عن مشاركتك في هذه الدراسة سرية. سيتم تخزين البيانات في كمبيوتر محمي بكلمة مرور ويوضع في خزانة مقفلة في مكتب مقفل ولا يمكن لأحد سوى الباحثين المشاركين في هذه الدراسة الدخول لهذه المعلومات.

لن يتم التعريف عنكِ في أي تقرير أو نشرة عن هذا البحث حيث أن البيانات كلها ستكون على شكل مجموعة وسيتم مسح جميع المعلومات الشخصية.

إلا أنه اذا تبيّن خلال المقابلة أنكِ أو أي شخص آخر في خطر جسيم فسيكون من واجب الباحثة مشاركة المعلومات مع الشرطة وفريق حماية الأطفال والبالغين

ماذا سيحصل في نهاية هذا البحث العلمي؟

سيتم نشر النتائج في مجلة متخصصة في التمريض. ولكن لن يكون في الامكان لأي شخص التعرف عليكِ أو على أي شخص آخر مشارك في الدراسة حيث سيتم إخفاء البيانات الشخصية. أيضاً سوف أكتب ملخص النتائج بصورة سهلة الفهم حتى يتسنى لك الاحتفاظ بنسخة منها.

ماذا إذا كان لدي أي مشكلة أو استفسار؟

إذا كان لديك أي استفسار بخصوص الدراسة فعليكِ أن تطلبي التحدّث مع الباحثة التي ستعمل جاهدة على الإجابة عن أسئلتك. عوضاً عن ذلك إذا كان لديك مشكلة مع طريقة الأسئلة المطروحة في المقابلة أو أي

استفسار آخر لا ترغبين بالتحدث عنه مباشرة مع الباحثة فبإمكانك التواصل مع المراقبين المشرفين على الباحثة بالطريقة التالية

Doctor Angela Morgan

[redacted]

Doctor Ranjit Khutan

[redacted]

إذا كنت ترغب في مناقشة المشاركة في هذه الدراسة مع شخص في المستشفى الذي لم يشارك في الدراسة، يرجى الاتصال بولا كلارك)مستشار القابلة (وهو المشرف للقابلات وسوف نكون سعداء لمناقشة أي مخاوف من أن لديك .يمكنك الاتصال بولا على:

أو الهاتف لوحة مفاتيح على [redacted] واطلب أن يكون [redacted] وضعت من خلال لبولا كلارك.

من قام بمراجعة هذه الدراسة؟

لقد تمت مراجعة هذه الدراسة العلمية من قبل لجنة الأخلاق البحثية في جامعة وولفرهامبتون ومن لجنة الأخلاق المختصة بالأبحاث التي تجري في المستشفى.

لمزيد من المعلومات

إذا أردتِ المزيد من المعلومات عن هذه البحث فلا تترددي في الاتصال بي على

[redacted]

أشكر لكِ اهتمامك

رقم الإصدار :3 تاريخ :7 يوليو 2016

مزيد من الدعم

قد تؤدي هذه الدراسة إلى الوراء بعض الذكريات التي هي مؤسفة، ومؤلمة و /أو غير سارة .وقد ضم الفريق الإشرافي البحوث و أستطيع أن قائمة الأسماء أدناه من المنظمات التي يمكن التحدث عن أي مخاوف ومؤلمة /ذكريات مزعجة .كل هذه الاتصالات C. / هي المهرة مع مساعدة النساء اللواتي تعرضن ختان الإناث

مركز المرأة أكتون حسنا أفريقيا، مركز صحي أكتون	**،كنيسة الطريق أكتون 61-35 W3 8QE ،غرب لندن**	020 8383 8761 020 8383 8712
عيادة المرأة الأفريقية، مستشفى كلية الجامعة	**عيادة 3، اليزابيث غاريت اندرسون الجناح، NW1 2BU**	0845 155 5000 ext. 2531
عيادة المرأة الأفريقية المرأة والصحة	**كارول شارع 4 كامدن، لندن، NW1 OTU**	0207 482 2786
عيادة النساء حسنا الأفريقي، مستشفى " جاى وسانت توماس	**ج /س قبل الولادة - 8 الطابقth لندن، Road عيادة، قصر لامبث SE1 7EH**	020 7188 6872 07956 542 576
،عيادة النساء حسنا الأفريقي مستشفى ويتنجتون	**مستوى 5 هاي جيت هيل، لندن N19 5NF**	020 7288 3482 ext. 5954 079566257992

برمنغهام وسوليهال المرأة المعونة	،بريستول شارع، برمنغهام 44-48 7AA B5	0121 685 8687 0808 800 0028
،عيادة النساء حسنا الأفريقي المستشفى المركزي ميدلسكس	،قبل الولادة عيادة، أكتون لين، لندن 7NS NW10	020 8963 7177 020 8965 5733
مركز وودفيلد الطبية قبل الولادة عيادة	W9 3XZ ،ودفيلد الطريق 7E	020 7266 8822
المرأة والشباب الشعبية الخدمات، سيلفيا مركز صحي بانكهيرست، مستشفى مايل إند	،لندن ،Road الطابق، بانكروفت 3 E1 4DG	020 7377 7870 020 7377 7898 020 8223 8322
عيادة مستشفى غرب لندن المرأة الأفريقية	مستشفى أمراض النساء ومتابعة ،الحوامل عيادات وتشيلسي وستمنستر SW10 9NH ،شارع فولهام 369	020 3315 3344
نوتنغهام المستشفيات الجامعية، مدينة الحرم الجامعي والعمل وارد الثقافات قبل الولادة عيادة	هوكنول الطريق NG5 1PB ،نوتنغهام شارع ولي العهد	0115 969 1169 ext. 55124 0151 702 4085
مستشفى ليفربول للنساء أقلية إثنية المرأة و عيادة بنات، شارلوت مركز صحي عارضة	L8 7SS ،ليفربول سيمور الطريق إيستون، بريستول BS5 0UA	0117 902 7111 0117 902 7100
مستشفى معاقل برمنغهام، أميرة ويلز وحدة المرأة، وارد العمل	الخضراء في الشرق Bordesley برمنغهام B9 5SS	0121 424 0730

Feuille de renseignements pour les participants

Vous sont invités à prendre part à une étude de recherche. Avant de vous décider, qu'il est important pour vous de comprendre pourquoi la recherche se faite et ce qu'elle implique. S'il vous plaît prenez le temps de lire attentivement les informations suivantes et en discuter avec des amis / parents. Nous demander si il ya quelque chose qui n'est pas clair ou si vous désirez plus d'informations. Prenez le temps de décider si oui ou non vous souhaitez participer. Je vous remercie pour cette lecture.

Titre de l'étude
Une étude rétrospective qualitative des expériences des femmes qui vivent avec les mutilations génitales féminines/excision (MGF/E) pour accéder aux services de maternité au Royaume-Uni

Que signifie le titre ?
L'étude demande postnatales femmes, victimes de femme circoncision ou génitale, coupant à un moment donné au cours de leur vie, leurs soins avec des médecins et des sages-femmes. Cela signifie que les soins que vous recevez de réunion initialement votre sage-femme de la Communauté, jusqu'à ce que vous avez eu votre bébé et sont rentrés chez eux.

Quel est le but de l'étude ?
L'étude est réalisée dans le cadre d'un doctorat en philosophie (PhD) à l'Université de Wolverhampton. Un doctorat est un diplôme universitaire qui consiste à effectuer des recherches dans le cadre de l'ensemble du projet. La personne qui effectue la recherche est Emma Danks qui est la sage-femme responsable de l'audit, des lignes directrices et de l'expérience des patients à l'hôpital de Birmingham femmes. Le but de l'étude est en cours pour déterminer comment les femmes qui ont subi des MGF / C pensaient des soins reçus pendant la grossesse, le travail et la période postnatale Autres buts de l'étude doivent comprendre que les femmes croient que les professionnels de la santé ont une compréhension culturelle de mutilation génitale féminine/excision et si leurs besoins sont réunies sous un angle culturel, émotionnel et physique par des sages-femmes et des médecins.
L'étude prendra environ 3 ans au total, mais la participation à l'étude de chaque femme sera pour une entrevue qui durera entre 30 et 45 minutes.

Pourquoi ai-je été à prendre part à cette étude??
Vous avez été invité à prendre part à cette étude parce que vous avez été identifié à avoir connu les MGF / E à un moment donné au cours de votre vie.

Ce que je dois prendre part ?
C'est à vous de décider de participer ou non. Si vous décidez de participer, que vous recevrez cette fiche d'information pour garder et demandera de signer un formulaire de consentement. Dans le cadre du formulaire de consentement, nous demander si nous pouvons regarder vos dossiers médicaux. Cela nous donnera une idée claire de la façon dont vous avez été pris en charge avant, pendant votre grossesse et après que vous avez

eu votre bébé. Vos dossiers ne seront pas regardé avant d'accepter en signant le formulaire de consentement. Si vous décidez de participer, vous êtes toujours libre de retirer à tout moment et sans donner de raison. Soyez assurés que si vous décidez de ne pas prendre part, cela n'affectera pas la norme de diligence que vous recevez.

Que se passera-t-il si je décide de prendre part ?
Bien que la recherche prendra environ 3 ans, pour terminer, votre participation sera pour l'entretien de 30 à 45 minutes et la discussion de 30-45 minutes pour discuter des conclusions à une date ultérieure (si vous choisissez de le faire). Au cours de l'entrevue, on vous demandera vos expériences des soins que vous avez reçu au cours de votre grossesse, du travail et après que vous avez eu votre bébé.L'entrevue aura lieu dans une salle sécurisée sans interruption de toute autre personne et sera bande enregistrée. Pour votre sécurité, la porte de la salle d'entrevue peut être verrouillé si vous le souhaitez. L'enregistrement est mémorisé dans un bureau sécurisé à l'intérieur d'une armoire verrouillée afin que personne n'a aucun accès à votre entrevue.
Vous êtes invités à participer à l'entrevue avant que vous êtes renvoyé à la maison de la salle postnatale, mais si vous avez choisi de retourner à l'hôpital pour participer à l'entrevue, le chercheur ne remboursera vos frais de voyage. S'il vous plaît discuter avec le chercheur avant de vous décider à prendre part.

Quels sont les avantages et les risques de participer ?
Bien qu'il n'y a aucun avantage direct pour vous si vous participez, en prenant part vous nous aidera à avoir une compréhension plus profonde des idées culturelles/MGF. Cela peut nous aider à améliorer la façon dont les femmes qui ont subi des MGF/E sont pris en charge à l'avenir.
Il n'y a aucun risque à vous en prenant part. Cependant, en prenant part, vous souvenez des choses qui pourraient vous être bouleversant. Dans ce cas, le chercheur vous demandera si vous voulez continuer à participer à l'entrevue. Toute décision que vous prenez est respectée.

Mon prenant part à l'étude resteront confidentiel ?
Oui. Toutes les informations concernant votre participation à cette étude resteront confidentielles. Les enregistrements et la transcription de l'entrevue, à que vous participez sont sauvegardées sur un ordinateur protégé par mot dans une armoire verrouillée dans un bureau verrouillé. Seuls les chercheurs travaillant sur le projet auront accès à ces renseignements. Vous ne serez pas identifiable dans toute publication ou le rapport que les données seront regroupées et toutes les informations d'identification seront supprimées. Toutefois, si quelque chose est déclenché lors de l'entrevue qui indique que vous ou quelqu'un d'autre est à risque de préjudice, alors ces préoccupations auront à prendre davantage. S'il y a une indication que vous ou quelqu'un d'autre est à risque de dommage significatif, alors c'est le devoir du chercheur de partager ces informations avec la Police et les locaux sauvegarde des équipes adultes et enfants. De même, si l'E / MGF a eu lieu au Royaume-Uni, il est du devoir du chercheur d'informer l'organisation de vos locaux la protection des enfants et la police.

Lorsque toutes les données ont été recueillies ensemble et la recherche a été publiée, tous les enregistrements et transcriptions d'interviews seront détruits. Ce sera un maximum de deux ans après que la recherche est terminée.

Que se passera-t-il à la fin de l'étude de recherche ?
Les résultats de la recherche seront publiés largement. Cependant, personne ne sera en mesure de vous identifier, ou toute autre personne qui prend part à la recherche comme toutes les données vont être rendus anonymes. Je vais aussi écrire une copie Sommaire des résultats dans un format facile à comprendre, afin que vous ayez la possibilité de garder une copie pour vous-même.

Que se passe-t-il si j'ai un problème ou une préoccupation ?
Si vous avez une préoccupation concernant tout aspect de cette étude, vous devriez demander à parler avec le chercheur qui va faire de leur mieux pour répondre à vos questions. Si vous avez des préoccupations au sujet de la façon dont les questions ont été posées ou pour toute autre question que vous ne souhaitez pas discuter directement avec le chercheur, vous pouvez également contacter les superviseurs du chercheur sur :

Docteur Angela Morgan [redacted]

Docteur Ranjit Khutan [redacted]

Si vous souhaitez discuter de la participation à cette étude avec quelqu'un à l'hôpital qui n'a pas participé à l'étude, s'il vous plaît communiquer avec [redacted] (Consultant Midwife) qui est un superviseur des sages-femmes et sera heureux de discuter de toutes les préoccupations que vous avez. Vous pouvez communiquer avec [redacted] sur:

[redacted] ou téléphoner au standard téléphonique sur [redacted] et demander à être mis en relation avec [redacted].

Qui a examiné l'étude ?
Cette étude a été examinée par le Comité d'éthique de recherche de l'Université de Wolverhampton et le Comité d'éthique qui examine les recherches avant les études menées à l'hôpital.
Contact pour plus d'informations
Si vous désirez des renseignements supplémentaires au sujet de l'étude, n'hésitez pas à me contacter sur :

[redacted]
Je voudrais saisir cette occasion pour vous remercier de votre intérêt pour cette étude.

Soutien supplémentaire

Cette étude peut ramener quelques souvenirs qui sont bouleversants, douloureux ou désagréable. L'équipe de recherche de supervision et moi avons inclus la liste de contacts ci-dessous des organisations qui peuvent parler à travers les peurs et souvenirs douloureux/bouleversant. Tous ces contacts sont qualifiés d'aider les femmes qui ont subi des MGF.

Acton d'africaines bien Centre, Centre de santé Acton	35-61 church Road Acton, Ouest de Londres, 8QE W3	020 8383 8761 020 8383 8712
Clinic des femmes africaines, University College Hospital	Clinique 3, Elizabeth Garrett Anderson aile, NW1 2 BU	0845 155 5000 ext. 2531
Clinique de la femme africaine Santé des femmes et des hommes	4, rue Carol Camden, London, NW1 OHU	0207 482 2786
Femmes africaines bien clinique, Guy et St Thomas' Hospital	8e étage – c/o clinique prénatale, Lambeth Palace Road, London SE1 7EH	020 7188 6872 07956 542 576
Clinique bien féminin en Afrique, Hôpital de Whittington	Niveau 5 Highgate Hill, Londres N19 5NF	020 7288 3482 ext. 5954 079566257992
Aide de Birmingham et Solihull féminin	44 – 48 Bristol Street, Birmingham, B5 7AA	0121 685 8687 0808 800 0028 (Numéro de téléphone fixe et GSM plus)
Clinique bien féminin en Afrique, Hôpital central de Middlesex	Clinique prénatale, Acton Lane, London, NW10 7NS	020 8963 7177 020 8965 5733
Woodfield Medical Centre Clinique prénatale	7e Woodfield Road, W9 3XZ	020 7266 8822
Des femmes et des jeunes Services, Centre de santé Sylvia Pankhurst, Hôpital Mile End	3e étage, Bancroft Road, London, E1 4DG	020 7377 7870 020 7377 7898 020 8223 8322
Hospital Clinic de la femme africaine de West London	Gynaecology et de centres de soins prénatals, de Chelsea et de Westminster Hospital, 369 Fulham Road, SW10 9NH	020 3315 3344
Nottingham University Hospitals, Campus de la ville, du travail de Ward	Hucknall Road Nottingham, NG5 1PB	0115 969 1169 ext. 55124
Clinique prénatale multiculturel Hospital de Liverpool Women's	Rue de la Couronne Liverpool, 7SS L8	0151 702 4085
Des femmes ethniques minoritaires et Clinique de filles, Centre de santé de Charlotte quille	Seymour Road Easton, Bristol BS5 0UA	0117 902 7111 (ligne directe) 0117 902 7100 (standard)
Birmingham Heartlands hôpital, princesse d'unité Galles féminine, travail Ward	Bordesley Green est Birmingham B9 5SS	0121 424 0730

Participant Information Sheet – Focus Group

You have been invited to take part in a Focus Group that is part of a research project. Before you decide it is important for you to understand why the focus group is part of the research project and what it will involve. Please take time to read the following information carefully and discuss it with friends/relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Study title

A qualitative retrospective study of the experiences of women who live with female genital mutilation accessing maternity services in the UK

What does the title mean?

The study is asking postnatal women, who have experienced female circumcision/genital cutting at some point during their life, about their care with doctors and midwives. This means the care that they receive from initially meeting their community midwife, until they have had their baby.

What is the purpose of the Focus Group as part of the study?

The purpose of the research is to investigate how women who have experienced FGM/C felt about the care they received during pregnancy, labour and postnatally. Further aims of the study are to understand whether women believe that health care professionals have a cultural understanding of FGM/C and if their needs have been met from a cultural, emotional and physical aspect by midwives and doctors. Therefore, the purpose of the Focus Group is a consultation and feedback event of the data that has been collected from the study participants. There will be opportunity to discuss the themes that emerge from the transcribed anonymised data and the cultural interpretation from a health care professional's perspective.

Why have I been invited to take part in the Focus Group?

You have been invited to take part in the Focus Group because you have been identified to have a cultural understanding of the communities and/or the women who have participated in the research.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Be assured that if you decide not to take part, this will not affect you.

What will happen if I decide to take part?

Although the final research project will take approximately 6 months to complete following the Focus Group, your participation will be for approximately one hour. There will be two sessions of the Focus Group held so that if you are unable to attend one due to other commitments, there will be opportunity to attend the other. During the Focus Group, the transcription of the collected data will be discussed and what the emerging themes of this data are. The Focus Group will take place in a room with no interruptions. The discussions during the Focus Group will be recorded onto a digital recording device. The digital recording device, along with any notes taken, as well as a transcription of the recording, will be kept in a secure office inside a locked cupboard so that no one has any access to the discussions that have taken place.

What are the potential benefits and risks of taking part in the Focus Group?

Though there are no direct benefits for you if you take part, by taking part you will help us to have a deeper understanding of the cultural ideas about FGM/C. This may help us to improve the way women who have experienced FGM/C are cared for in the future.

There are no risks to you in taking part in this Focus Group. However, by taking part, you may read about things that you may find upsetting. If this occurs, the researcher will ask you if you want to continue to participate in the Focus Group. Any decision you make will be respected. The researcher has provided the participants with contact details of organisations who provide specialist care to women who have experienced FGM/C; these organisations also provide counselling services for women. A list of these has also been provided to you if you find any of the discussions upsetting and you feel that you need to talk through any of your concerns.

Will my taking part in the study be kept confidential?

Yes, any information shared or any discussion that takes place will remain within the confines of the Focus Group. The recording and transcription of the Focus Group that you will participate in will be stored as described above. Access to any of this information is only granted to those outlined on the consent form, namely the researcher, individuals at the University of Wolverhampton, regulatory authorities or the NHS Trust where the research takes place. You will not be identifiable in any publication or report as the data will be grouped together; any identifying information will be removed.

When the Focus Group is complete and all of the information has been collected together and analysed and the research has been published, the recording and transcription of the Focus Group will be destroyed. This will be a maximum of two years after the research has been completed.

If anything is raised during the Focus Group that indicates that either you or someone else is at risk of harm, then these concerns will have to be taken further. If there is an indication that you or someone else is at risk of significant harm then it is the duty of the researcher to share this information with the Police and local safeguarding adult and children's teams. Equally, if FGM/C has occurred in the UK, it is the duty of the researcher to inform the local safeguarding adult and children's organisations and the police.

What will happen at the end of the research study?

The findings of the research will be disseminated widely. However, no one will be able to identify you or anyone else that takes part in the research as all data will be anonymised. I will also provide a summary copy of the findings in a format that is easy to understand so that you have the opportunity to keep a copy for yourself.

What if I have a problem or concern?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions. Alternatively, if you have any concerns about the way that the Focus Group is carried out or any other concerns that you do not wish to discuss with the researcher directly, you may contact the researcher's supervisors on:

Dr Angela Morgan

[redacted]

[redacted]

Dr Ranjit Khutan

[redacted]

[redacted]

If you wish to discuss this with someone who is not connected to the study, Consultant Midwife [redacted], who is also a Supervisor of Midwives, will discuss any concerns you have about the study.

[redacted]

You may also contact the switchboard on [redacted] and ask for [redacted]

Who has reviewed the study?

This study has been reviewed by the Research Ethics Committee of the University of Wolverhampton and South Birmingham Research Ethics Committee/Health Research Authority (HRA).

Contact for further information

If you would like any further information regarding the study, please do not hesitate to contact me on:

Emma.Danks@wlv.ac.uk

Emma.Danks1@nhs.net

I would like to take this opportunity to thank you for your interest in this study.

Acton African Well Women Centre, Acton Health Centre	35-61 Church Road Acton, West London, W3 8QE	020 8383 8761 020 8383 8712
African Women's Clinic, University College Hospital	Clinic 3, Elizabeth Garrett Anderson Wing, NW1 2BU	0845 155 5000 ext. 2531
African Women's Clinic Women & Health	4 Carol Street Camden, London, NW1 OHU	0207 482 2786
African Well Women's Clinic, Guy's and St Thomas' Hospital	8th Floor – c/o Antenatal Clinic, Lambeth Palace Road, London SE1 7EH	020 7188 6872 07956 542 576
African Well Women's Clinic, Whittington Hospital	Level 5 Highgate Hill, London N19 5NF	020 7288 3482 ext. 5954 079566257992
Birmingham and Solihull Women's Aid	44 – 48 Bristol Street, Birmingham, B5 7AA	0121 685 8687 0808 800 0028 (Freephone from landline and most mobile numbers)
African Well Women's Clinic, Central Middlesex Hospital	Antenatal Clinic, Acton Lane, London, NW10 7NS	020 8963 7177 020 8965 5733
Woodfield Medical Centre Antenatal Clinic	7e Woodfield Road, W9 3XZ	020 7266 8822
Women's and Young People's Services, Sylvia Pankhurst Health Centre, Mile End Hospital	3rd Floor, Bancroft Road, London, E1 4DG	020 7377 7870 020 7377 7898 020 8223 8322
West London African Women's Hospital Clinic	Gyanecology and Antenatal Clinics, Chelsea and Westminster Hospital, 369 Fulham Road, SW10 9NH	020 3315 3344
Nottingham University Hospitals, City Campus, Labour Ward	Hucknall Road Nottingham, NG5 1PB	0115 969 1169 ext. 55124
Multi-Cultural Antenatal Clinic Liverpool Women's Hospital	Crown Street Liverpool, L8 7SS	0151 702 4085
Minority Ethnic Women's and Girls Clinic, Charlotte Keel Health Centre	Seymour Road Easton, Bristol BS5 0UA	0117 902 7111 (direct line) 0117 902 7100 (switchboard)
Birmingham Heartlands Hospital, Princess of Wales Women's Unit, Labour Ward	Bordesley Green East Birmingham B9 5SS	0121 424 0730

Appendix III

Consent Forms

CONSENT FORM

Title of Project:
A qualitative retrospective study of the experiences of women who live with female genital mutilation accessing maternity services in the UK

Name of Researcher: Emma Danks
Please initial boxes

I confirm that I have read and understand the information sheet dated 7th July 2016 (version 3) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time[30], without giving any reason. ☐

I understand that my data will be stored securely and confidentially[31] and that I will not be identifiable in any report or publication ☐

a. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals at the University of Wolverhampton, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research and for the duration of the study. ☐

b. I give permission for these individuals to have access to my records. ☐

c. I understand that my medical records will not be looked at until I have signed this consent form. ☐

I understand that the researcher may wish to publish this study and any results found, for which I give my permission ☐

I agree for my interview to be recorded on a digital audio device and for the data to be used for the purpose of this study. ☐

I agree to take part in the above study. ☐

……..	……..	……
Name	Date	Signature
……..	……..	……
Name of person taking consent (if different from researcher, state position)	Date	Signature
……	……	……
Researcher	Date	Signature

[30] For some studies it may be difficult to withdraw an individual participant's data (e.g. following interviews and conducting qualitative thematic analysis). In such circumstances participants can only withdraw their data up until the commencement of the data analysis. Also data is collected anonymously I may not be able to identify the data to subsequently remove it.

[31] If safeguarding issues are raised the information may not be kept fully confidential and may be shared with relevant organisations.

استمارة موافقة

عنوان البحث:
دراسة نوعية بأثر رجعي عن تجربة النساء اللائي خضعن للختان مع الخدمات الطبية للحوامل في المملكة المتحدة

اسم الباحثة: إيما دانكس

الرجاء وضع √ في المربع

1. لقد قرأت وفهمت ورقة المعلومات بتاريخ ..... (النسخة 1 أو 2) للدراسة المذكورة أعلاه و أتيحت لي الفرصة لطرح الأسئلة ☐

2. أعلم بأن المشاركة طوعية وأني حرة في الانسحاب من هذه الدراسة في أي وقت بدون اعطاء الأسباب ☐

3. أعلم بأن الباحثة قد ترغب بنشر هذه الدراسة ونتائجها ولا مانع لدي من ذلك ☐

4. ا .وأنا أفهم أن الأجزاء ذات الصلة من ملاحظاتي الطبية والبيانات ☐
جمعت أثناء الدراسة يمكن النظر فيها من قبل الأفراد في جامعة ولفرهامبتون، من السلطات التنظيمية أو منفيو، حيث أنها ذات الصلة لاتخاذ جهتي في مجال البحث و
.لمدة الدراسة

.ب .أعطي الإذن لهؤلاء الأفراد في الحصول على سجلاتي ☐

ج. وأنا أفهم أنه لن يتم النظر السجلات الطبية في بلدي حتى ولدي
.وقع هذا النموذج موافقة

وأنا أفهم أن قد يرغب الباحث لنشر هذه الدراسة ☐
وجدت أية نتائج، الذي أعطي إذن مني

5. أنا أوافق على مقابلتي ليكون الشريط المسجل على جهاز الصوت الرقمي
.وللبيانات لاستخدامها لغرض هذه الدراسة

6. .أنا أوافق على المشاركة في الدراسة المذكورة أعلاه ☐

بالنسبة لبعض الدراسات أنه قد يكون من الصعب سحب البيانات مشاركا الفردية)مثل التالية المقابلات وإجراء التحليل الموضوعي النوعي .(في مثل هذه الظروف يمكن للمشاركين فقط سحب البيانات الخاصة بهم حتى بدء تحليل البيانات .كما يتم جمع البيانات مجهول قد لا تكون قادرة على تحديد البيانات إلى إزالته .في وقت لاحق

.إذا تم رفع قضايا حماية لا يجوز إبقاء المعلومات سرية تماما، ويمكن أن تكون مشتركة مع المنظمات ذات الصلة 2

الاسم	التاريخ	التوقيع
.....	.....	.....
Signature	Date	Researcher

FORMULAIRE DE CONSENTEMENT

Titre du projet:
Une étude rétrospective qualitative des expériences des femmes qui vivent avec les mutilations génitales féminines pour accéder aux services de maternité au Royaume-Uni.

Nom du chercheur : Emma Danks

S'il vous plaît les cases initiales

Je confirme que j'ai lu et comprendre la fiche d'information datée datée 07/07/2016 (version 3) pour étudier ce qui précède et d'eu l'occasion de poser des questions. ☐

Je comprends que ma participation est volontaire et que je suis libre de retirer à tout moment[1], sans indication de motif. ☐

Je comprends que mes données seront conservées en toute sécurité et confidentialité[2] et que je ne serai pas identifiable dans tout rapport ou une publication ☐

4. a. Je comprends que les sections pertinentes de mes notes médicales et des données recueillies au cours de l'étude peut être regardé par des personnes à l'Université de Wolverhampton, des autorités réglementaires ou de la
NHS Trust, où il est pertinent de ma participation à la recherche et pendant toute la durée de l'étude. ☐

b. Je donne la permission pour ces personnes d'avoir accès à mes dossiers. ☐

c. Je comprends que mes dossiers médicaux ne seront pas regardé jusqu'à ce que je dois signé le présent formulaire de consentement. ☐
Je suis d'accord pour mon entrevue à être enregistrées et pour classer les données utilisé dans le but de cette étude. ☐

Je suis d'accord participer à l'étude ci-dessus ☐

…… ……. ……
Nom Date Signature

…… ……. ……
Nom de la personne qui prend consentement(s'il est différent d'un chercheur, préciser le poste) Date Signature

…… ……. ……
Chercheur Date Signature

[1]Pour certaines études, il peut être difficile de retirer les données d'un participant individuel (par exemple suite à des entretiens et de mener une analyse thématique qualitative). Dans de telles circonstances, les participants ne peuvent retirer leurs données jusqu'au début de l'analyse des données. Aussi les données sont recueillies de façon anonyme, je ne peux pas être en mesure d'identifier les données à supprimer ultérieurement.
[2]Si les problèmes de sauvegarde sont soulevées les informations peuvent ne pas être pleinement confidentiel et ne peut être partagée avec les organisations concernées.

CONSENT FORM – Focus Group

Title of Project:
A qualitative retrospective study of the experiences of women who live with female genital mutilation accessing maternity services in the UK

Name of Researcher: Emma Danks
Please initial boxes

I agree to participate in the Female Genital Mutilation focus group carried carried out by Emma Danks to aid with the research identified in the project title (above). ☐

I have read version 1 (dated 7th July 2016) of the information sheet related to the research project and fully understand the contents of this. ☐

I am aware of the topics to be discussed in the focus group. ☐

I am aware that my identity will remain anonymous throughout the data reporting and that I may leave the focus group at any time. ☐

I am aware that any data collected during the focus group will be collected via a digital recording device as well as notes being taken and will be stored in a locked cupboard within a locked office that will only be accessible to the researcher (named above). ☐

I am aware that the anonymised data collected will be accessible to Individuals at the University of Wolverhampton, regulatory authorities or from the NHS Trust where the research takes place. ☐

I am aware that the tape recording of the focus group will be transcribed following the focus group. ☐

I agree to take part in the focus group. ☐

…….	…….	……
Name	Date	Signature
…….	…….	……
Name of person taking consent	Date	Signature
…….	…….	……
Researcher	Date	Signature

Appendix IV

Recommendations from the Bar Human Rights Committee

The BHRC's Recommendations to the UK Parliament (as at February 2014)

1. **Introduce 'FGM Protection Orders' (FGMPOs)** modelled on Forced Marriage Protection Orders and Sexual Offences Prevention Orders. FGMPOs would prohibit respondents from carrying out FGM, prevent children at risk of FGM from being removed from the jurisdiction, and ensure the repatriation of survivors from abroad.
2. **Criminalise FGM for all children taken out of UK** to be mutilated, irrespective of whether 'settled' or not: the UK's legal obligations extend to all children within its jurisdiction – therefore UK organisers of such mutilations should face prosecution, irrespective of the child's status.
3. **Establish an Anti-FGM Unit.** There should be a central institution for the UK's anti-FGM response, equivalent to the Forced Marriage Unit in the Foreign and Commonwealth Office.
4. **Pass a legal requirement for mandatory training and reporting for frontline professionals** in regulated services (health, social care, education).
5. **Increase resources for combating FGM** in accordance with the UN resolution that state responses to the elimination of FGM should be properly resourced.
6. **Provide medical and emotional support for survivors**. The UK's international obligations require that effective remedial support for survivors is available, such as reconstructive (reversal) surgery and emotional/psychological support.
7. **Challenge cultural justifications for FGM** wherever they arise**;** be clear that this (i) accords with international consensus; (ii) is the stance of the United Nations; and (iii) forms part of the UK's international obligation to modify cultural or traditional practices that are harmful to women and girls.
8. **Launch national awareness-raising campaign** which must emphasise that FGM is (i) a gross human rights violation; (ii) a crime and child abuse; (iii) a problem in and for British society, which we have a moral and legal duty to combat.
9. **Introduce FGM into the National Curriculum**. Education about FGM is required for boys and girls to foster empowerment and personal autonomy among girls and respect for women's rights and bodies among boys.
10. **Create community engagement programmes.** Develop a programme of sensitive, properly resourced community engagement projects to change attitudes about FGM. Community members should be encouraged to help run such initiatives.
11. **Deprecate the marginalisation of migrant communities.** Racially demeaning depictions, whether in press, public or political debate, or through governmental action, further isolate migrant communities and act to perpetuate FGM as a form of social solidarity and identity.
12. **Monitor FGM and collect data** to fill the knowledge gap about the incidence and distribution of FGM and monitor the effectiveness of the UK's interventions.

Appendix V

Interview Questions

The interviews will be semi structured allowing the participant to elaborate on any questions that they wish. Participants will be given the opportunity to decline any questions that they do not wish to answer.

1. Does your community support circumcision of females?
2. How do you feel about Western Society's views of female circumcision?
3. How do you feel when someone uses the term "FGM"? (Does this reflect your own feelings/beliefs?)
4. Tell me about your feelings when you discovered that you were pregnant.
5. Tell me about the support you received during your pregnancy.
6. Tell me about your labour experience. (Particularly about the care you received from doctors and midwives).
7. If your circumcision was discovered when you were in labour, tell me how you felt about this.
8. Did you know that midwives have a duty to report all cases of female circumcision as part of a national data collection and safeguarding children? How do you feel about this?
9. Is there anything that you would like to tell me about your care in the maternity services?

Appendix VI

FGM Survivor One-to-one interview discussion guide

(i) Explore experiences of care prior to pregnancy related to FGM

a. *Why was this care provision accessed?*
b. *Who was the main health care professional providing this care?*
c. *Were there any barriers to accessing care?*
d. *Was any information provided (was this helpful)?*
e. *Was an aftercare provided (where appropriate)?*

(ii) Explore the experiences of care during pregnancy

a. *What were your feelings when you discovered you were pregnant?*
b. *Who was the first health care professional you discussed your pregnancy with?*
c. *Was FGM discussed during this appointment? If so, how was this approached?*
d. *Did this health care professional discuss any referrals to others due to FGM?*
e. *Did you access an FGM clinic? If so, can you tell me about your experience of this?*
f. *Was FGM discussed at any other time during your pregnancy? If so, can you tell me about this?*
g. *Can you tell me about the plan for your labour and birth? (who helped you to plan for this?)*
h. *Can you tell me about decisions that were made during your pregnancy about your care? (Did you feel that you were involved with decision making?)*

(iii) Explore the experiences of care following the labour and birth

a. *Can you tell me about your labour and birth experience?*
b. *Who was involved with your care during this time?*
c. *Did you have a re-arranged birth plan? (was your birth plan adhered to?)*
d. *Can you tell me about your labour and birth experience? (were you involved in any decision making where required?)*
e. *Was pain relief offered to you (or did you have the opportunity to discuss this)?*
f. *If any procedures were needed as a result of your FGM, were these discussed with you? (If so, who discussed these with you?)*
g. *Can you tell me about your feelings following the birth of your baby?*

h. *Were you moved to a different ward following the birth? (Can you tell me about your feelings at that time?)*
i. *Can you tell me about your experience on that ward?*

Appendix VII

Health Care Professionals Focus Group Discussion Guide

(i) Explore the care available to FGM survivors prior to pregnancy

a. *What encompasses pre-pregnancy care?*
b. *Are you aware of any specific pre-pregnancy services available to FGM survivors (such as mental health/psychological care, deinfibulation services or contraception and conception care?)*
c. *Can you tell me about the kind of services (outside of pregnancy) that would be helpful for FGM survivors?*

(ii) Explore the care provided to FGM survivors at the beginning of pregnancy

a. *Can you tell me about your experience of providing care to FGM survivors at the initial maternity appointment?*
b. *Can you tell me how questions are asked relating to FGM?*
c. *Can you tell me about the specific referral pathways for FGM survivors?*
d. *Can you tell me how safeguarding referrals are discussed with FGM survivors? (Can you tell me about the importance of safeguarding involvement?)*
e. *Can you tell me your opinions on the use of the word 'concern' in documentation?*
f. *Can you tell me about mental health care referrals for FGM survivors?*
g. *What can you tell me about clinical guidelines on FGM? (Do you think that any changes are needed in these?)*

(iii) Explore the care provided to FGM survivors during pregnancy

a. *Does the routine maternity care pathway differ for FGM survivors? (How?)*
b. *What can you tell me about the FGM clinic?*
c. *How is the type of FGM diagnosed? (By whom?)*
d. *Who ascertains the mode of birth? (Does this form part of the woman's birth plan?)*
e. *What are you views on discussing the law around FGM with FGM survivors?*

(iv) Explore the care provided to FGM survivors during labour and birth

a. *Can you tell me about the labour and birth pathway for FGM survivors? (Does this differ from the normal labour and birth pathway?)*
b. *Can you tell me about pain relief options for women in labour? (Is this the same for FGM survivors?)*
c. *What are your views on pain relief for FGM survivors?*
d. *What kind of information is given (or needed) for type 3 FGM survivors following the birth?*
e. *What are your views on labour and birth debriefs for FGM survivors?*

(v) Explore the care provided to FGM survivors in the immediate postnatal period (from transfer to the postnatal area until discharge from hospital)

a. *What are your views on postnatal care overall?*
b. *In your opinion, should postnatal care for FGM survivors differ from the normal pathway of postnatal care? (How/why?)*
c. *Is it necessary to discuss legal aspects of FGM to survivors postnatally if this has been discussed antenatally? (Why?)*
d. *In your opinion, should culture be taken into account on the postnatal wards? (How?)*
e. *What can you tell me about FGM awareness training and education overall?*

Appendix VIII

FGM Survivors Focus Group Discussion Guide

(i) Explore views on health care education

a. *Health care education is provided by (and developed by) health and social care professionals as well as legal professionals. What are your views on this?*
b. *In your opinion, how is the best way to approach health care education?*
c. *In your opinion, who should be involved in health care education? (e.g. development and delivery).*

(ii) Explore views on health care regulation and statutory duty

a. *Health care professionals have a statutory and legal duty to make referrals to safeguarding teams when individuals meet the criteria. What are your views on this?*
b. *What are your views on health care regulation?*

Appendix IX
Ethics Approvals

Date 24.12.14

Emma Danks
University of Wolverhampton
FEHW

Dear Emma Danks

Re: Re-review - A qualitative retrospective study of the experiences of women who live with female genital mutilation accessing maternity services in the UKsubmitted to The Faculty of Education, Health and Wellbeing Ethics Panel (Health Professions, Psychology, Social Work & Social Care)

The Faculty Ethics Panel (Health Professions, Psychology, Social Work & Social Care) has considered and reviewed your submission.

On review your Research Proposal was passed and given approval **Code 2 – Approved Subject to Conditions.** The conditions for Approval are below.

A. Researcher/Supervisor to Monitor. Please address the minor amendments detailed below. If this is student research, supervisors must ensure the minor amendments have been completed prior to commencement of data collection.

Suggested Changes

- The consent form and letter could be made more simple – they are currently quite academic.

Required Changes

- Ensure that withdrawal on the consent form equates to that described in the protocol – i.e. up until anonymisation of data.not any time
- Q8 is incomplete

Best wishes in the future.

Yours sincerely

[redacted]

Re: Amendments to Study

Date 11th March 2016

(Name)
University of Wolverhampton
Faculty of Education, Health & Wellbeing

Dear Emma Danks

Re: Project submitted to The Faculty of Education, Health and Wellbeing Ethics Panel (Health Professions, Psychology, Social Work & Social Care)

The Faculty Ethics Panel (Health Professions, Psychology, Social Work & Social Care) has considered and reviewed your proposed minor amendements.

On review your Revised Research Proposal was passed and the Panel believes that the ethical issues inherent in your study remain adequately considered and addressed. Therefore the Panel is giving you full ethical approval for your revised study (**Code 1 - Approved**). We would like to wish you every success with the project.

Yours sincerely

[redacted]
Chair – Ethics Panel

[redacted]
Chair – Ethics Panel

NHS
Health Research Authority
West Midlands - South Birmingham Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 August 2016

Mrs Emma L Danks
Midwife
Birmingham Women's NHS Foundation Trust
Birmingham Women's Hospital
Mendelsohn Way
Birmingham
B15 2TG

Dear Mrs Danks

Study title:	**A qualitative retrospective study of The experiences of women who live with female genital mutilation (FGM) accessing maternity services in the UK.**
REC reference:	**16/WM/0278**
Protocol number:	**N/A**
IRAS project ID:	**137251**

Thank you for your letter of 28th July 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Assistant, [redacted], nrescommittee.westmidlands-southbirmingham@nhs.net.

NHS
Health Research Authority

Mrs Emma L Danks
Midwife
[redacted]
Email: hra.approval@nhs.net

18 August 2016

Dear Emma

Letter of HRA Approval

Study title:	**A qualitative retrospective study of The experiences of women who live with female genital mutilation (FGM) accessing maternity services in the UK.**
IRAS project ID:	**137251**
Protocol number:	**N/A**
REC reference:	**16/WM/0278**
Sponsor	**University of Wolverhampton**

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

[redacted]

NHS

Research & Development Department

R&D Director : [redacted]

R&D Manager [redacted]

[redacted]

Mrs E Danks

[redacted]

09/09/2016

Dear Emma,

Re: A qualitative retrospective study of 'The experiences of women who live with female genital mutilation (FGM) accessing maternity services in the UK'.
HRA Approval Letter : 18th August 2016
Ethics Ref : 16/WM/0278
Local R&D Ref : 16/BWH/NO02
IRAS Ref : 137251

Protocol : v3 07.07.2016
Participant Information Sheet (English, French and Arabic) : v3 07.07.2016
Participant Information Sheet Focus Group : v1 08.07.2016
Participant Consent Form (English, French and Arabic) : v3 07.07.2016
Participant Consent Form Focus Group : v1 08.07.2016
Letters of Invitation to Participant (English, French and Arabic) : v3 07.07.2016
Interview Schedule : v3 08.07.2016

This letter confirms that [redacted] Trust has the capability and capacity to deliver the above mentioned study.

Please note that approval is granted subject to the following conditions:

- If you have not already done so you must ensure that you and other members of the research team complete Good Clinical Practice ('GCP') training and a copy of your certificate is forwarded to the R&D Department before conducting your research.

Appendix X
Letter of Access

Date: 26th April 2016

Private and Confidential
Strictly Addressee Only
Emma Danks
[redacted]

Dear Emma,

Re: FGM Women Data Collection

I am writing to confirm that I will authorise your request to collect data from the groups of women that you have requested in order to support your PhD Studies.

I do hope that your application to R & D is accepted and wish you the best for completion of your PhD.

If you have any queries in the meantime please do not hesitate to contact myself or my PA [redacted]

Yours sincerely

Appendix XI
(i) Sample Coding – FGM Survivor

Transcript 020	Coding
ED: Can I just check that this is your signature in the consent form?	Service provision
FS20: Yes that's correct	Clinical procedures
ED: What is your view of the way that you experience care when you have accessed services anywhere have been cared for and treated when you have accessed care?	Support
FS20: My experience has been overwhelmingly positive definitely. My first encounter was around 15 years ago when I decided that I wanted to have a reversal of FGM. The way that came about was at that time about 15 years ago, there wasn't any services available in Birmingham. At that time if you wanted anything you had to go to London and I was fortunate that I mentioned it to a couple of friends, one of who was a nurse and then she read an article in the Times I think it was about a consultant in Middlesex hospital in London about an African well women's clinic which was relatively new around that time. So I contacted that hospital and I had all of my treatment there. It was interesting – Dr was amazing and her carried out my operation but the day I had to go to the pre assessment, I took a friend along who was an elderly white lady and most people who were in there were African. Lots of women had Hiqabs on so and then one of the consultants came up to me and he said and said hello I will be seeing you later. But he was really frosty which I thought was a bit strange. So I said to my friend, do you think he was a bit weird with me? She didn't pick anything up but I felt really strange about this and was confused as to why. So I had the consultation and he examined me and said yes we can operate and he gave me a date. I then had the operation and that was all really good. Apart from the fact that pre-op, I don't know who it was, a doctor or a nurse, came in and wanted me to sign a disclaimer form. I had my gown on and everything. I had the presence of mind to read	Culture Negative feelings Poor communication Anxiety Positive feelings Positive experience of HCP Explanation Assumption Language barrier HCP knowledge-poor Religion HCP knowledge-good Sexual health Choice

through the text first and they had accidentally put sterilisation. So I saw this and said, this shouldn't be here. The person said yes that is an error but I thank god that I spotted it! They crossed it off and apologised. That was a bit unnerving! The operation itself went really well I was really happy with it. The nurses were lovely, I had a male nurse which I was a bit disconcerted at first but he was the best nurse I had the whole time; he was fantastic. Then I had to go back to the post-operative clinic – I think I had about two. When I went to the first post-operative one, the same doctor who had been a bit frosty with me initially, did the post-operative said he needed to apologise to me because the first time we met he was sharp with me – I knew I hadn't imagined it! He said it was because they had had journalists – African female journalists – pretending that they needed treatment and coming to the clinic. A lot of the women I noticed there – I think it was a lot of refugees – there had been a whole influx at the time. An awful lot of them had broken English and as I was with a white lady he had that trigger thinking that oh she's a journalist because he wouldn't be expecting to see a white woman in that clinic

and so he apologised for that which was good because I was wary of being treated by someone who was a bit stone faced – so that was nice. Then I pretty much got better. Then I was at uni training to be a social worker so I had to get well and carry on studying. Oh then I had a bad episode, at the well women's clinic they had a counsellor. It's not compulsory but they still advise you to have post-operative therapy and there was an in house lady – someone who has written a book actually – she was the therapist allocated to me – the problem was that I was a student living in Birmingham and I didn't have a lot of money to travel the 100 or so miles [so it wasn't practical] although the sessions were free which was good but it was the time and money because I was doing a vocation degree and it was very demanding with placements. But in the end I said I would like to come but I can't get to London that often but they said oh we have telephone sessions so I had a couple of telephone sessions with her and I honestly found her attitude appalling. By then I had developed PTSD. I was having

Anxiety

Negative feelings

Service provision

Mental Health concern

HCP knowledge-poor

Religion

Assumption

HCP knowledge-good

Positive experience of HCP

flashbacks; I can't sleep so she told me I needed to learn how to masturbate and that was the only bit of advice that she offered me (laughs). I said that I will worry about the masturbation later! I was Muslim but I converted to Christianity six days prior to that. She said that I need to "break free of the shackles" and basically said that I was suffering from neurosis and said I had all the restrictions of Islam and needed to explore my sexuality and learn to be Christian and learn to masturbate and be free. She didn't know whether I masturbated or not! She said I will send you some books on masturbation. So I just left that service. The PTSD then got worse.

Then when I was unwell and went to my GP I was very fortunate. My GP surgery at that time had received a bursary and they could employ a therapist and asked me if I would be interested in seeing this lady for four months because [he] could have given me lots of antidepressants but felt that I needed to talk things through – it was good advice. [She] was great, just talking things through was great. I had always just coped really and it was better than antidepressants. Although it takes longer to stop them but at the end of the day I am not addicted. So I saw a sex therapist. So I had recovered I'd say from the PTSD.

ED: do you have any issues with mental health now?

FS20: No I feel ok now

ED: You have done amazingly

FS20: Thank you. It has taken a long time and a lot of help but I am glad that I had those. I have had 3 relapses – 2 bad ones and one mild but each time I have had the therapy. I have hit difficult patches but I know roughly what my triggers are. The therapist has taught me self-awareness, what my triggers are and when to remove myself from a situation. So in terms of services that I have experienced – quite mixed, on the whole really good. When I got pregnant it was amazing. 15 years ago in Birmingham there was nothing and now there is so much awareness so it is really good – a lot in maternity and to [see how things have] changed, it's a completely different landscape now.

When I had my reversal, I didn't have any fear of becoming pregnant and I'm very fortunate to have a good supportive husband. I feel secure and I am with the right person and it was the right time.

ED: so in terms of maternity services, did you feel supported by the maternity services itself?

FS20: In terms of the maternity services, I would say are fantastic. I have seen four different people. My community midwife is the only one I haven't had an entirely positive experience with. My [1st appointment contact] when I was pregnant and I was anxious about giving birth – although I wasn't completely anxious about giving birth – we all know it's not [a walk in the park don't we] (laughs). I was seeing a specialist nurse . It's a very long story but basically when I was engaged and about to get married I was a virgin and I said to my GP that I just wanted an examination to check that everything was ok and that it was functioning properly. If she hadn't seen my medical notes she said she wouldn't even have known that I had been circumcised which was unheard of. She said I was physically very small down there and recommended getting dilators to make sure everything was comfortable so she referred me to the women's hospital to a lady called [name] who did all of that so my first experience of the womens was a positive not a negative. But it was not due to the FGM but to my physiology. When I got pregnant she asked me how I felt about childbirth, and I said to be honest I feel fine about childbirth but my concern was around tearing and stitches and that because I know that when I had 2 bad bouts of PTSD it was after something happened which caused flashbacks to the original event. My reversal was positive but was another event that triggered flashbacks. So my concerns were more around not having PTSD because it would have interfered with my relationship. I have a family completely dependent on me so I didn't want to feel depressed, weepy, low, and it wouldn't have been an ideal emotional state to been looking after a child. So I just wanted to come and think about maybe having an elective caesarean to avoid that possibility. I was supported and was referred to the consultant midwife who talked through the elective caesarean with me or

Support

Positive experience of HCP

Anxiety

Sexual health

Positive feelings

Mental Health concern

Choice

Negative feelings

a natural birth and I decided to go down the elective caesarean route although the doctors were against it

ED: you need to do what's right for you

FS20: Yes and everyone had been really understanding about that. But back to my original point, [name] was great and [name] was brilliant and beyond what I was expecting and if I had PTSD I would be offered post-birth counselling.

ED: yes, you could have been offered lots of support and services either in the hospital or from external services

FS20: Yes I was and it was a lot more than I expected. I wasn't sure whether consultant midwife would be my advocate or I would need to fight for it myself which I was prepared to do however it was really nice when she said to me that with your history you can have an elective and said that she wanted to lay that on the table so that I could just relax. But then go through my options so I didn't feel that I had to fight for what I wanted. But it was really helpful for me to do this because I was able to explore natural birth without the fear and I could relax and genuinely explore my options so that was helpful. Also because I was an older mum I would have a consultant as well as a midwife and she has been fantastic as well but my cmw was the only time I haven't felt supported because she doesn't really listen to what I am trying to express. The first meeting we had when we were filling in my book was quite long – it was 1 and a half hours. I was trying to talk about the FGM as it was in the green notes and it was a bit distressing – we were talking about the FGM and she wanted to know my attitude around vaginal birth and how I would want to give birth so I just explained to her what I've explained to you all my concerns lie around triggers – I am in a happy marriage and if I had PTSD that would really affect my marriage and bonding with my baby would be affected so I'm not sure that I want a natural birth. She said it's not like you have [an un-ordinary cervix] you are just giving birth. We talked about it for a while because I hadn't talked about FGM for a while. So at the end she said I'll just write down that you have a phobia of childbirth and she wrote I had tocophobia. Which is not the case. I was really upset

Positive feelings

Hesitant

Positive experience of HCP

Choice

Poor communication

Anxiety

Seeking views

Mental Health concern

Dismissive

Negative experience of HCP

about this. I told her that it was not a true reflection of how I felt. It made me feel that the whole time we had talked about it that she hadn't really listened to me or heard me – that's how it felt. She did eventually cross it out.

Whenever I see her she is always very brusque – when you see a midwife you need care not tick boxes. I was 10 mins late and I came in the door and she shouted at me for being late - I had SPD so couldn't walk fast. She constantly was patronising to me – she tells me that she has told me things but she hadn't. I was relieved when I didn't need to see her again.

ED: this is a caring profession and that is what a midwife should do – care for people. I am sorry that this happened.

FS20: I always felt that I had to apologise for taking up her time.

5 minute discussion regarding a complaint about the midwife** request not to use this in the interview transcript

FS20: If I was younger she would have been the only person for me to see to ask questions and I would have been scared to ask her.

ED: that appointment is your platform for you to ask about things you aren't sure of or to ask questions

FS20: I didn't want to ask any questions because I felt hurried but I needed to feel that I understood what was happening. So the whole episode of maternity it was only my community midwife in pregnancy that I wasn't happy with.

In theatre people were aware of my PTSD – it was apparent that people were aware and treated me with care. I was given a say and when I wanted my catheter put in. It was wonderful actually and a lot of thought had gone into it.

It was over and above what I expected. The level of awareness was really good

Dismissive

Negative experience of HCP

Mental Health concern

Choice

Consent

Poor communication

ED: we try as hard as we can with training and we think we have made it a really important thing for all staff to have an awareness. One of the main things is safeguarding referrals – how do you feel about this

FS20: I have heard about this – what does it involve?

ED: We have to raise a cause for concern for all women – how do you feel about that

FS20: Do they do it for boys as well?

ED: the thinking around it is any female children at all in the family. What we have tried to bring in is that there is no cause for concern for boys.

FS20: Will I be participated in that? If I am having a boy?

ED: from a national perspective yes, all women

FS20: So who will be informed?

ED: Your GP and health visitor will have been informed. You will have been told that a cause for concern was completed. Did anyone tell you this?

FS20: No. I don't want that. My child will not be in danger. Do I have the option to refuse that? I can see why they do this but I can give consent or not?

ED: usually it is done when the midwife sees you at first. They have to tell you.

FS20: My midwife didn't tell me any things.

Further discussion about complaint – currently in progress

ED: if we feel that someone is at significant risk then the HCP might withhold this – but so far this has not been known.

FS20: Does this go to social services?

ED: this is only if a child is at risk of significant harm

FS20: The name of the document is scary; I don't obviously want to block this if it is a positive thing but I would like to have a discussion and details of how it works. Would I have to sign it? Would you have a look through my notes to see if it is there?

ED: Yes. Usual practice would be to document in your notes that you are against the practice.

FS20: No one has discussed this with me and it hasn't been documented in my notes. I haven't been to the FGM clinic Poor communication

FS20: Can I check the time please?

ED: Yes, its 25 past.

FS20: Thank you. Can you check for the cause concern please.

ED: Yes I will have a look through your notes.

FS20: Thank you very much

End

Service provision

there wasn't any services available in Birmingham. At that time if you wanted anything you had to go to London

consultant in Middlesex hospital in London about an African well women's clinic which was relatively new around that time

there was an in house lady – someone who has written a book actually – she was the therapist allocated to me

the problem was that I was a student living in Birmingham and I didn't have a lot of money to travel the 100 or so miles [so it wasn't practical] although the sessions were free which was good but it was the time and money

I can't get to London

	15 years ago in Birmingham there was nothing and now there is so much awareness so it is really good – a lot in maternity and to [see how things have] changed, it's a completely different landscape now.
	My GP surgery at that time had received a bursary and they could employ a therapist and asked me if I would be interested in seeing this lady for four months
Clinical procedures	So I had the consultation and he examined me and said yes we can operate and he gave me a date. I then had the operation and that was all really good
	Dr was amazing and he carried out my operation
Support	I took a friend along who was an elderly white lady and most people who were in there were African
	I'm very fortunate to have a good supportive husband. I feel secure and I am with the right person and it was the right time
	I was supported and was referred to the consultant midwife
Culture	Lots of women had Niqabs on
	A lot of the women I noticed there – I think it was a lot of refugees
Negative feelings	he was really frosty which I thought was a bit strange
	I felt really strange about this and was confused as to why

	Oh then I had a bad episode, at the well women's clinic they had a counsellor
	although the doctors were against it
	I honestly found her attitude appalling.
Poor communication	they had accidentally put sterilisation
	he had that trigger thinking that oh she's a journalist because he wouldn't be expecting to see a white woman in that clinic
	my community midwife was the only time I haven't felt supported because she doesn't really listen to what I am trying to express
	at the end she said I'll just write down that you have a phobia of childbirth and she wrote I had tocophobia
	It made me feel that the whole time we had talked about it that she hadn't really listened to me or heard me – that's how it felt
	My midwife didn't tell me any things
	No one has discussed this with me and it hasn't been documented in my notes
Anxiety	That was a bit unnerving!
	because I was wary of being treated by someone who was a bit stone faced
	I was anxious about giving birth

	but my concern was around tearing and stitches
	I was trying to talk about the FGM as it was in the green notes and it was a bit distressing
Positive feelings	My experience has been overwhelmingly positive definitely
	The operation itself went really well I was really happy with it
	She said I was physically very small down there and recommended getting dilators to make sure everything was comfortable so she referred me to the women's hospital to a lady called [name] who did all of that so my first experience of the womens was a positive not a negative.
	Yes I was and it was a lot more than I expected
Positive experience of HCP	The nurses were lovely, I had a male nurse which I was a bit disconcerted at first but he was the best nurse I had the whole time; he was fantastic
	but felt that I needed to talk things through – it was good advice. [She] was great, just talking things through was great
	It has taken a long time and a lot of help but I am glad that I had those
	she referred me to the women's hospital to a lady called [name] who did all of that so my first experience of the womens was a positive not a negative
	In terms of the maternity services, I would say are fantastic

	Yes and everyone had been really understanding about that. But back to my original point, [name] was great and [name] was brilliant and beyond what I was expecting and if I had PTSD I would be offered post-birth counselling
	it was really nice when she said to me that with your history you can have an elective and said that she wanted to lay that on the table so that I could just relax
Negative experience with HCP	My community midwife is the only one I haven't had an entirely positive experience with
	I was really upset about this. I told her that it was not a true reflection of how I felt
	I was 10 mins late and I came in the door and she shouted at me for being late
	She constantly was patronising to me – she tells me that she has told me things but she hadn't. I was relieved when I didn't need to see her again.
	I always felt that I had to apologise for taking up her time
	If I was younger she would have been the only person for me to see to ask questions and I would have been scared to ask her
	So the whole episode of maternity it was only my community midwife in pregnancy that I wasn't happy with
	My midwife didn't tell me any things
Explanation	the same doctor who had been a bit frosty with me initially, did the post-operative said he needed to

	apologise to me because the first time we met he was sharp with me – I knew I hadn't imagined it
Assumption	He said it was because they had had journalists – African female journalists – pretending that they needed treatment and coming to the clinic
	he had that trigger thinking that oh she's a journalist because he wouldn't be expecting to see a white woman in that clinic
	She said that I need to "break free of the shackles" and basically said that I was suffering from neurosis and said I had all the restrictions of Islam
	She didn't know whether I masturbated or not! She said I will send you some books on masturbation
Language barrier	An awful lot of them had broken English and as I was with a white lady
Mental Health concern	By then I had developed PTSD. I was having flashbacks; I can't sleep
	The PTSD then got worse. Then when I was unwell and went to my GP I was very fortunate
	I have had 3 relapses – 2 bad ones and one mild but each time I have had the therapy. I have hit difficult patches but I know roughly what my triggers are
	2 bad bouts of PTSD it was after something happened which caused flashbacks to the original event
	was another event that triggered flashbacks

	I didn't want to feel depressed, weepy, low, and it wouldn't have been an ideal emotional state to been looking after a child
	I just explained to her what I've explained to you all my concerns lie around triggers
	In theatre people were aware of my PTSD – it was apparent that people were aware and treated me with care
HCP knowledge-poor	she told me I needed to learn how to masturbate and that was the only bit of advice that she offered me
	She said it's not like you have [an un-ordinary cervix] you are just giving birth
	at the end she said I'll just write down that you have a phobia of childbirth and she wrote I had tocophobia. Which is not the case.
Religion	Lots of women had Hiqabs on
	She said that I need to "break free of the shackles" and basically said that I was suffering from neurosis and said I had all the restrictions of Islam
	needed to explore my sexuality and learn to be Christian and learn to masturbate and be free
	I was Muslim but I converted to Christianity six days prior to that.
HCP knowledge-good	The therapist has taught me self-awareness, what my triggers are and when to remove myself from a situation
Sexual health	about to get married I was a virgin and I said to my GP that I just wanted an examination to check that everything was ok and that it was functioning properly

	my concerns were more around not having PTSD because it would have interfered with my relationship
	I had always just coped really and it was better than antidepressants. Although it takes longer to stop them but at the end of the day I am not addicted. So I saw a sex therapist
Choice	think about maybe having an elective caesarean to avoid that possibility
	who talked through the elective caesarean with me or a natural birth and I decided to go down the elective caesarean route
	But then go through my options so I didn't feel that I had to fight for what I wanted. But it was really helpful for me to do this because I was able to explore natural birth without the fear and I could relax and genuinely explore my options so that was helpful
	I was given a say and when I wanted my catheter put in.

(ii) Sample Coding – Health Care Professional's Focus Group

Transcript 021

Focus Group thematic coding (phase 2 analysis)

Data	Sub-theme	Overarching Theme
01. they are used to talking to women who need extra support like that. Although I think there are doctors in the clinic as well. But I didn't see any when I was there because I was in the room with the [name] the whole time. So yes, sensitive communication is key with this group of women because they are particularly vulnerable. *(HCP01)* *02.* yes, doctors also provide care in the clinic, usually for women who need more complex care planning like women with a type III who have got lots of scar tissue or if the scarring has interfered with the urethra and so on. *(HCP03)* *03.* Where I work, in my Trust, all these women would be referred to the vulnerable women midwives. Basically, they are the ones that diagnose FGM. I think, I don't know, but I think they get extra training than we do. *(HCP09)* *04.* we can't always guarantee that a birth plan will be followed to the letter because of the fast changing environment that delivery suite is. I've been a shift leader on there for a while and some women do accept this but others do get upset about it but we do try to keep women informed of what's happening but sometimes we have to give them that explanation after the event if it's a particular emergency. *(HCP07)*	**Providing complex information**	**Communication**

Data	Sub-theme	Overarching Theme
01. Plus, whatever happens in the clinic I think that specialist midwives ask these women specific questions about their FGM so it's not just about safeguarding. I think sensitive communication is key with this group of women because they are particularly vulnerable. Those midwives talk to vulnerable women all the time so they are used to talking to women who need extra support like that. *(HCP01)* *02.* we can't always guarantee that a birth plan will be followed to the letter because of the fast changing environment that delivery suite is. I've been a shift leader on there for a while and some women do accept this but others do get upset about it but we do try to keep women informed of what's happening but sometimes we have to give them that explanation after the event if it's a particular emergency. *(HCP07)* *03.* I can understand the conversation but is a ward the right place to have this conversation with women? That doesn't seem very private to me to be talking about that kind of thing. *(HCP08)* *04.* The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *(HCP01)* *05.* So the guidelines for caring for women tell you to talk to them about the law? How is that care? It seems like scare mongering to me. I can see the point but doing that in an open ward? *(HCP08)* *06.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *(HCP04)* *07.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it *(HCP09)*	**Difficult conversations**	**Communication**

Data	Sub-theme	Overarching Theme
01. Would these women be treated differently to normal women? Most women would have smear tests and things like that at their GP surgery wouldn't they? *(HCP01)* *02.* I get what you're saying about differentiating between FGM women and women who haven't got FGM, but what IS normal? Can you point at one and say "yeah, that's normal"? What about women with tattoos, piercings and that? Are they normal 'cus I wouldn't do that? I couldn't think of anything worse to be honest! That's the difference between normal and not for me *(HCP02)* *03.* There are differences in what we class as normal or not. But when [name] was talking about it, I think what you're saying is the woman's normal, it's the FGM that isn't? Is that what you meant? *(HCP04)* *04.* it isn't normal is it? I mean to do that, like cutting bits off a young girls genitals just for the sake of it. What is normal about that? But I do get what you're saying. Yeah, but I suppose we are so used to thinking of FGM women as not normal that it kind of [pauses] you kind of start thinking of the women as not normal rather than her vagina not being normal. *(HCP01)* *05.* I agree, yes, we see FGM in notes and the woman becomes the FGM. It's not just her genitalia. This is something that needs to change. It's like we are calling the woman FGM! I wonder if we've just used this [pause] I don't know, I want to say in a lazy way but not, if you know what I mean? I can't remember what the online thing says, or guidelines for that matter. *(HCP05)* *06.* This goes back to what I was saying about women becoming FGM. It's something that's so easily said. We've all said it so it just goes to show how embedded that is. *(HCP05)*	**Agency and labelling**	**Knowledge and education**

Data	Sub-theme	Overarching Theme
01. but we can't just go and do what we feel like without discussing it with the woman and her agreeing to it first! So hopefully, all women understand what is happening during labour because we shouldn't – and couldn't – do anything without her consent. That goes for all women, so whether she has FGM or not. What if she didn't understand what was going on? She wouldn't be consenting to what we were doing then! That's a whole can of worms *(HCP03)* *02.* it's really important that women understand what is happening when they are on delivery suite, not that I work on there [laughs]. But seriously, if anything goes wrong and they didn't understand then it would be the fault of whoever was looking after her. Look at this woman there [points at the screen], these women who have deinfibulation need to understand what happens after, she didn't know what was going to happen by the look of it so did she really consent to this? It makes me wonder, after all, we are changing their genitalia which changes the way things like passing urine is and especially this woman here who felt like her insides were falling out! So yeah, making sure women understand it important, actually THE most important thing that we should be doing. *(HCP04)* *03.* doing things like that we have to consent then which means they understand the benefits and risks of it. We can't just go around doing deinfibulations on women just like that can we? I mean, if they didn't say they consented to it then we couldn't do it but it would mean that they can't have a normal delivery then would it? So we have to also weigh up the benefits and risks. It's better for her to have a normal delivery anyway, cus she'll recover better afterwards. *(HCP02)* *04.* but are those women saying they consent or are they taking your word for it that it's the best thing for them? You might be assuming they understand when they might not really. Look at this woman here, [points to the screen] she didn't understand by the look of it how the blood would come out after. She says here that she felt like her insides were falling out. Surely she didn't understand? *(HCP08)*	**Consent**	**Knowledge and education**

01. Well the vulnerable women midwives do some kind of training *(HCP09)* *02.* well, there's that training but there is also the online training that we all should do. It's part of our mandatory training so everyone should have done it. It is a bit basic, and to be honest with you […] at least we are getting some training for these women *(HCP07)* *03.* No I mean the training isn't enough really. It doesn't tell us anything about culture or what we should or shouldn't do […] but I'm not from that culture; I know nothing about FGM's culture. I do know some bits that we 've been told but yeah that's it. There's nothing in there [pauses] anywhere really that tells us about this *(HCP03)* *04.* and more to the point, we haven't got a clue about the culture of this but we are supposed to be telling these women what is best for them and their baby. So if a woman's pregnant and I'm talking to her about what's best, how do I know if I don't know what her culture is? Now I say that, it's worrying really when you think about it *(HCP04)* *05.* Sometimes I do wonder whether they probably think we're interfering in something we don't know about. It's a bit like going back to the old colonial times probably *(HCP05)* *06.* I don't think it's as strong as colonialism, but I do think there is a lack of understanding on our part. *(HCP07)* *07.* I disagree, we are trying to get a culture that we know nothing about to agree to our culture, all the things that we think are right without a second thought to how it might make them feel. So personally, I agree with [name] talking about it being colonialism because if that isn't colonialism I don't know what is! *(HCP04)* *08.* To me, this shows that the training is just not good enough. *(HCP03)* *09.* the training is really to identify the types of FGM, which is done in the clinic really not by the community midwives. I'm not sure what happens there but where I work, it's either a doctor or vulnerable women midwives do this I'm guessing, is that right [name-referring to HCP07]. I've never worked in this clinic so I don't know to be honest *(HCP05)* *10.* I think they get extra training than we do *(HCP09)*	**Lack of knowledge and cultural knowledge**	**Knowledge and education**

Data	Sub-theme	Overarching Theme
11. Well like we said the guidelines say the women should be referred to an FGM clinic. I don't know what they do in these clinics, as far as I know they do all the care planning there. Obviously I look at the woman's notes after but yeah, I don't know what goes on there *(HCP01)*		
01. I don't think women feel like they're being controlled at all. The women understand that the practice is wrong. I remember a woman who I met with about 15 years ago who had arranged for her daughter to be cut. A few families had arranged for a cutter to be flown over to the UK to cut a few girls. The woman regretted having her daughter cut and went to the police to tell them what had happened. The case was referred to social services and the social services decided that it was not in the best interests of the child to be removed from the family home because they considered it [FGM] as a one-off form of physical abuse. They also said that they did not consider it in the best interests of the child to remove the mother as they believed that the child had an otherwise loving environment. It makes me wonder how many times and how many children have slipped through the net *(HCP08)*	**Culture of FGM**	**Knowledge and education**
01. we have no choice, they have to refer all women who have had FGM.I think that it is safest for all that they make the referral. I don't really discuss the referral with the women anyway because what can we do? Isn't it the law that we have to make the referral? Whether the woman likes it or not they have to refer them to the FGM clinic and to the safeguarding team. I suppose it depends on safeguarding whether they refer them [the women] to social services. I don't remember anyone being referred to social services though *(HCP04)*	**Statutory regulation**	**Service provision and statutory regulation**

01. we have to follow the guidelines and any kind of referrals made are dictated by whatever guidelines say. If we start ignoring the guidelines then what's the point of having them? Guidelines are based on evidence of what the best care is. So we follow these because it has been proved that this is the best thing to do. Guidelines aren't just thrown together, they are collected by best evidence that's why it's called evidence-based practice *(HCP09)* *02.* if it's in the guidelines to make the referral, then that's what we have to do. It's up to the woman or not whether she goes, but thinking about it, if it's something to do with safeguarding and she doesn't go to the clinic, I'm thinking safeguarding are informed anyway *(HCP07)* *03.* In investigations, I know notes are scrutinised against guidelines, I've seen it and I've been involved in doing so many investigations where the care is compared to what's in those guidelines. If someone hasn't followed them to the letter then they are hauled over the coals! But these investigation show whether we have given safe care or not, you know, the five questions and that. *(HCP07)* *04.* I don't think there's a difference at all! I can't even see why one's called policies and one's called guidelines to be honest because to us, policies and guidelines are the same because we are judged on all of it. If we don't follow the guidelines like policies then we know about it! *(HCP01)* *05.* Yes, they might be called guidelines but we don't have a choice whether we follow guidelines or not. If the guidelines say that the woman should be referred then we refer the women. If we didn't refer a woman, then someone else would. Even if I see a woman in say antenatal clinic at 36 weeks, I would still have to refer the woman if she was picked up then *(HCP06)* *06.* usually when women come in in labour they already have a birth plan that's been done in the clinic or by the community midwife. Although we can't always stick to it, sometimes the birth plan goes out the window because of things like failure to progress or abnormal CTGs and things like that. *(HCP01)* *07.* I do think that it's a nice idea but at the end of the day, our job is to make sure we have a well mum and a well baby. We have to assess that risk all the time and sometimes that means we can't see other women as much as we'd like to. Can you imagine the CQC if we had to explain that one on one of the five questions? *(HCP02)*	**Meeting performance indicators**	**Service provision and statutory regulation**

Data	Sub-theme	Overarching Theme
08. The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *(HCP01)* *10.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *(HCP04)* *11.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it *(HCP04)* *12.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this. *(HCP08)*		

Data	Sub-theme	Overarching Theme
01. So I know that there is a clinic over in [place] but that's it really around this area isn't it? Although we are all expected to do it, actually, I'm not sure you midwives are as expected to do it as us lot [laughs] but yeah, if a woman comes in in labour, then if we are on [pause] although I would probably defer to the senior reg [laughs]. But seriously, if we are talking about pre-pregnancy, I only know of [name] clinic because deinfibulation is quite specialist so they are concentrated in areas like London aren't they? I'm guessing that there is a bigger population of FGM women there, I don't know [pause] I'm not sure of the need around here, I might be wrong. *(HCP06)* *02.* The trouble is, you're talking about a really small number of women compared to the number of women who actually access the services. I do know about [name's] clinic but that's the only one really in the Midlands isn't it? To be honest, I don't think there's any services really that's specific to FGM survivors other than [name's] service anywhere near here because its quite niche isn't it. So it wouldn't be a priority for the NHS budget I reckon considering all the other things that are really important like diabetes and smoking which seem to be the hot topics at the moment *(HCP07)* *03.* pre-pregnancy care isn't just about deinfibulation is it? Surely these women would need some kind of conception advice, especially type III women? Also, what about smears and other sexual health? *(HCP03)* *04.* Ok, so what I understand the vulnerable women midwives looks after women who are vulnerable, like mental health issues, teenage pregnancy, drug users and all things like that. *(HCP06)* *05.* Yes, I think they do all the safeguarding stuff in the clinic for the women and the ones that need type III opening is sorted there as far as I know, that's it but the safeguarding bit is important. To be honest, apart from the opening thing, I don't know how they are different from our vulnerable women clinics *(HCP09)*	**Service commissioning and need**	**Service provision and statutory regulation**

Data	Sub-theme	Overarching Theme
01. Well, yeah, that's a really nice and in theory it would be a great idea, but who would do it? There aren't enough midwives or doctors as it is to cover one shift on delivery suite let alone start offering extra services like that *(HCP02)* *02.* I can see that as well. What about talking to women after they have delivered? Would that be a better option than creating a whole new service? The women are already there and wouldn't have to go back in to talk about it. Come to think of it, they might not be bothered to come back or might be too busy with their new baby *(HCP08)* *03.* There is no way that I would have time to talk to women after delivery. I mean, well I just wouldn't have time to sit and talk about anyone's labour and delivery because when I'm on shift I have to cover more than just delivery suite, I am spread out really thinly and I could be needed anywhere in the hospital. So I could be half way through a debrief with a woman about her labour and that and be called to an emergency at the other end of the hospital. That would take priority. *(HCP05)* *04.* See the doctors wouldn't have time and neither would the midwives, there just isn't enough of us to do something like that. I mean [pauses] for example, [pauses] yes, when I'm on delivery suite, I could be looking after a labouring woman and as soon as she has delivered I would have to go to another woman straight away. So there isn't time to sit with people and go through it afterwards. *(HCP09)*	**Care debriefing**	**Service provision and statutory regulation**
01. I don't think [pauses] I think that women don't want to say about their FGM at booking because of the referrals they know we will make. With all the hype in the news about FGM I think they are scared to talk to us about it. But really, all we want to do is make sure that they have the support they need, and their pregnancy and delivery are safe. *(HCP02)*	**Referral to other agencies**	

01. Well, yeah, that's a really nice and in theory it would be a great idea, but who would do it? There aren't enough midwives or doctors as it is to cover one shift on delivery suite let alone start offering extra services like that *02.* There is no way that I would have time to talk to women after delivery. I mean, well I just wouldn't have time to sit and talk about anyone's labour and delivery because when I'm on shift I have to cover more than just delivery suite, I am spread out really thinly and I could be needed anywhere in the hospital. So I could be half way through a debrief with a woman about her labour and that and be called to an emergency at the other end of the hospital. That would take priority. *(HCP05)* *03.* See the doctors wouldn't have time and neither would the midwives, there just isn't enough of us to do something like that. I mean [pauses] for example, [pauses] yes, when I'm on delivery suite, I could be looking after a labouring woman and as soon as she has delivered I would have to go to another woman straight away. So there isn't time to sit with people and go through it afterwards. *(HCP09)* *04.* I do think that it's a nice idea but at the end of the day, our job is to make sure we have a well mum and a well baby. We have to assess that risk all the time and sometimes that means we can't see other women as much as we'd like to. Can you imagine the CQC if we had to explain that one on one of the five questions? *(HCP02)* *05.* Unfortunately it's a problem that we can't solve. It will always be like this so unless we have more midwives it will always be like this *(HCP04)* *06.* Going back to women feeling like they are left alone. When we are allocating midwives to a shift, it depends how busy delivery suite is as well, that is the biggest factor here so if there are more women in labour than midwives, which happens a lot, then midwives have to be pulled from postnatal wards which always leaves them short but on the balance of risk we don't have a lot of choice. It all boils down to [pauses] at the end of the day, our first priority is to make sure everyone is safe which means everyone so that goes for the midwives as well, we have to make sure that they are safe *(HCP07)* *07.* Most definitely yes! I don't want to lose my pin number because of the amount of women I have to look after on delivery suite! It's too dangerous on delivery suite sometimes to not pull the postnatal midwives! The other thing [pauses] well, postnatal care isn't called the 'Cinderella service' for nothing! Sometimes there can be only one midwife to quite a few women, sometimes 10 or 11 who also have babies and all those women and babies, they should have a	**Staffing issues**	**Service provision and statutory regulation**

Data	Sub-theme	Overarching Theme
postnatal check every day and then go through a checklist when they go home but that's it unless they have any problems. So I do understand how they have it as well *(HCP01)*		

01. I don't think there's a difference at all! I can't even see why one's called policies and one's called guidelines to be honest because to us, policies and guidelines are the same because we are judged on all of it. If we don't follow the guidelines like policies then we know about it! *(HCP01)* *02.* theoretically, policies and guidelines are different, but in this line of work they may all be called policies because we have to follow them whatever *(HCP07)* *03.* Yes, they might be called guidelines but we don't have a choice whether we follow guidelines or not. If the guidelines say that the woman should be referred then we refer the women. If we didn't refer a woman, then someone else would. Even if I see a woman in say antenatal clinic at 36 weeks, I would still have to refer the woman if she was picked up then *(HCP06)* *04.* Well like we said the guidelines say the women should be referred to an FGM clinic. I don't know what they do in these clinics, as far as I know they do all the care planning there. Obviously I look at the woman's notes after but yeah, I don't know what goes on there *(HCP01)* *05.* I think yeah, safeguarding is important for these women. OK, it might not be the woman herself who agrees with FGM, but what about her family or someone else? Children have slipped through the net before, not with FGM but with other things. If we haven't referred women to the clinic and something happens, who's to blame? They would blame us for not referring her, for not following the guidelines! *(HCP02)* *06.* It depends on who the woman sees, it could be a doctor or a midwife but it will be someone who is trained to make the diagnosis *(HCP05)* *07.* but how accurate can a picture be? I think that to do proper care planning, they would need to see exactly what's happening down there. Although it's a bit worrying with that woman there [points at the screen] when the doctor got it wrong *(HCP09)* *08.* this woman looks like she felt forced into it. But I can see both points of view here, they would need to do a risk assessment of whether this woman could deliver. It would be awful if this woman turned up in labour or worst still, turned up for induction and they couldn't do it because she was type III. So yeah, I think the examinations are needed antenatally. *(HCP04)*	**Institutional culture**	**Service provision and statutory regulation**

Data	Sub-theme	Overarching Theme
09. it would mean that they can't have a normal delivery then would it? So we have to also weigh up the benefits and risks. It's better for her to have a normal delivery anyway, cus she'll recover better afterwards *(HCP02)* *10.* The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *(HCP01)* *11.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *(HCP04)* *12.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it *(HCP09)* *13.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this. *(HCP08)*		

Data	Sub-theme	Overarching Theme
01. I think it's difficult with FGM women because an FGM midwife isn't a mental health specialist and a mental health specialist midwife isn't an FGM midwife. I don't know but as far as I know a mental health midwife will get the same FGM training as the rest of us and an FGM midwife will get the same mental health training as the rest of us. I don't know any different so someone correct me on that [pauses]. So really I don't think either of them could look after the other's area better than the rest of us *(HCP04)* *02.* I agree and well, mental health assessment needs to be done by the GP so when women raise mental health concerns, guidelines tell us to refer them to their GP *(HCP03)* *03.* at the minute if we pick up mental health issues we would refer to the GP. Well, that's what our guidelines say anyway and I would follow that because there is nothing in the guidelines about referring between the two midwives *(HCP07)* *04.* I'm just thinking, so, if these midwives look after mental health women, why can't they do the mental health care for FGM women as well? Although, I would worry about those like [pause] especially with the woman earlier with PTSD. So it's a good idea but mental health care for FGM women, that would need to be specific wouldn't it? Like trauma counselling? *(HCP05)*	**Disjointed service provision**	**Mental health care and issues**

01. I just wonder how much damage has been done to these women, especially in women with PTSD like this woman. What she really needed was some support. This just shows that there needs to be more, I don't know, mental health support for FGM women. *(HCP08)* *02.* it might not be because of the FGM had it? It might be because of moving here and being isolated, or like the woman with PTSD because of deinfibulation. I think there are so many things that could cause a woman to need support, we just have be better at knowing why she needs support. *(HCP02)* *03.* I think it's difficult with FGM women because an FGM midwife isn't a mental health specialist and a mental health specialist midwife isn't an FGM midwife. I don't know but as far as I know a mental health midwife will get the same FGM training as the rest of us and an FGM midwife will get the same mental health training as the rest of us. I don't know any different so someone correct me on that [pauses]. So really I don't think either of them could look after the other's area better than the rest of us *(HCP04)* *04.* I'm just wondering though, what about if the midwives were in the same place so one could knock on the door to other, that kind of thing? And couldn't there be something joined like mental health and FGM? Like both specialist midwives doing training about it or something? *HCP01)* *05.* I'm just thinking, so, if these midwives look after mental health women, why can't they do the mental health care for FGM women as well? Although, I would worry about those like [pause] especially with the woman earlier with PTSD. So it's a good idea but mental health care for FGM women, that would need to be specific wouldn't it? Like trauma counselling? *(HCP05)* *05.* But that's assuming that all women with FGM have PTSD, we can't assume that *(HCP07)* *06.* are we saying that all women are traumatised? Really? Maybe there are some women traumatised, but the question is why are they? The woman earlier sounds like she was more traumatised by the deinfibulation and it sounds like the counselling just made it worse! So joint training, yeah, which would help us understand but it doesn't help the women does it? A joint clinic might work though. I think that's a good idea *(HCP02)* *07.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this. *(HCP08)*	**Lack of mental health training and understanding**	**Mental health care and issues**

(iii) Sample Coding – Dominant Discourses

Transcript 021

Isolated Dominant Discourses – Focus Group

Data	Overarching Theme	Dominant Discourses
01. they are used to talking to women who need extra support like that. Although I think there are doctors in the clinic as well. But I didn't see any when I was there because I was in the room with the [name] the whole time. So yes, sensitive communication is key with this group of women because they are particularly vulnerable. *02.* yes, doctors also provide care in the clinic, usually for women who need more complex care planning like women with a type III who have got lots of scar tissue or if the scarring has interfered with the urethra and so on. *03.* Where I work, in my Trust, all these women would be referred to the vulnerable women midwives. Basically, they are the ones that diagnose FGM. I think, I don't know, but I think they get extra training than we do. *04.* we can't always guarantee that a birth plan will be followed to the letter because of the fast changing environment that delivery suite is. I've been a shift leader on there for a while and some women do accept this but others do get upset about it but we do try to keep women informed of what's happening but sometimes we have to give them that explanation after the event if it's a particular emergency.	**Communication**	**Antenatal Care** **Risk Assessment** **Accountability** **Cultural Care**
01. Plus, whatever happens in the clinic I think that specialist midwives ask these women specific questions about their FGM so it's not just about safeguarding. I think sensitive communication is key with this group of women because they are particularly vulnerable. Those midwives talk to vulnerable women all the time so they are used to talking to women who need extra support like that. *02.* we can't always guarantee that a birth plan will be followed to the letter because of the fast changing environment that delivery suite is. I've been a shift leader on there for a while and some		

Data	Overarching Theme	Dominant Discourses
women do accept this but others do get upset about it but we do try to keep women informed of what's happening but sometimes we have to give them that explanation after the event if it's a particular emergency. *03.* I can understand the conversation but is a ward the right place to have this conversation with women? That doesn't seem very private to me to be talking about that kind of thing. *04.* The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *05.* So the guidelines for caring for women tell you to talk to them about the law? How is that care? It seems like scare mongering to me. I can see the point but doing that in an open ward? *06.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *07.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it		
01. Would these women be treated differently to normal women? Most women would have smear tests and things like that at their GP surgery wouldn't they? *02.* I get what you're saying about differentiating between FGM women and women who haven't got FGM, but what IS normal? Can you point at one and say "yeah, that's normal"? What about women with tattoos, piercings and that? Are they normal 'cus I wouldn't do that? I couldn't think of anything worse to be honest! That's the difference between normal and not for me *03.* There are differences in what we class as normal or not. But when [name] was talking about it, I think what you're saying is the woman's normal, it's the FGM that isn't? Is that what you meant?	**Knowledge and education**	**Antenatal Care** **Risk Assessment** **Accountability** **Cultural Care**

Data	Overarching Theme	Dominant Discourses
04. it isn't normal is it? I mean to do that, like cutting bits off a young girls genitals just for the sake of it. What is normal about that? But I do get what you're saying. Yeah, but I suppose we are so used to thinking of FGM women as not normal that it kind of [pauses] you kind of start thinking of the women as not normal rather than her vagina not being normal. *05.* I agree, yes, we see FGM in notes and the woman becomes the FGM. It's not just her genitalia. This is something that needs to change. It's like we are calling the woman FGM! I wonder if we've just used this [pause] I don't know, I want to say in a lazy way but not, if you know what I mean? I can't remember what the online thing says, or guidelines for that matter. *06.* This goes back to what I was saying about women becoming FGM. It's something that's so easily said. We've all said it so it just goes to show how embedded that is.		
01. but we can't just go and do what we feel like without discussing it with the woman and her agreeing to it first! So hopefully, all women understand what is happening during labour because we shouldn't – and couldn't – do anything without her consent. That goes for all women, so whether she has FGM or not. What if she didn't understand what was going on? She wouldn't be consenting to what we were doing then! That's a whole can of worms *02.* it's really important that women understand what is happening when they are on delivery suite, not that I work on there [laughs]. But seriously, if anything goes wrong and they didn't understand then it would be the fault of whoever was looking after her. Look at this woman there [points at the screen], these women who have deinfibulation need to understand what happens after, she didn't know what was going to happen by the look of it so did she really consent to this? It makes me wonder, afterall, we are changing their genitalia which changes the way things like passing urine is and especially this woman here who felt like her insides were falling out! So yeah, making sure women understand it important, actually THE most important thing that we should be doing. *03.* doing things like that we have to consent then which means they understand the benefits and risks of it. We can't just go around doing deinfibulations on women just like that can we? I mean, if they		

Data	Overarching Theme	Dominant Discourses
didn't say they consented to it then we couldn't do it but it would mean that they can't have a normal delivery then would it? So we have to also weigh up the benefits and risks. It's better for her to have a normal delivery anyway, cus she'll recover better afterwards. *04.* but are those women saying they consent or are they taking your word for it that it's the best thing for them? You might be assuming they understand when they might not really. Look at this woman here, [points to the screen] she didn't understand by the look of it how the blood would come out after. She says here that she felt like her insides were falling out. Surely she didn't understand?		
01. Well the vulnerable women midwives do some kind of training *02.* well, there's that training but there is also the online training that we all should do. It's part of our mandatory training so everyone should have done it. It is a bit basic, and to be honest with you […] at least we are getting some training for these women *03.* No I mean the training isn't enough really. It doesn't tell us anything about culture or what we should or shouldn't do […] but I'm not from that culture; I know nothing about FGM's culture. I do know some bits that we've been told but yeah that's it. There's nothing in there [pauses] anywhere really that tells us about this *04.* and more to the point, we haven't got a clue about the culture of this but we are supposed to be telling these women what is best for them and their baby. So if a woman's pregnant and I'm talking to her about what's best, how do I know if I don't know what her culture is? Now I say that, it's worrying really when you think about it *05.* Sometimes I do wonder whether they probably think we're interfering in something we don't know about. It's a bit like going back to the old colonial times probably *06.* I don't think it's as strong as colonialism, but I do think there is a lack of understanding on our part.		

Data	Overarching Theme	Dominant Discourses
07. I disagree, we are trying to get a culture that we know nothing about to agree to our culture, all the things that we think are right without a second thought to how it might make them feel. So personally, I agree with [name] talking about it being colonialism because if that isn't colonialism I don't know what is! *08.* To me, this shows that the training is just not good enough. *09.* the training is really to identify the types of FGM, which is done in the clinic really not by the community midwives. I'm not sure what happens there but where I work, it's either a doctor or vulnerable women midwives do this I'm guessing, is that right [name-referring to HCP07]. I've never worked in this clinic so I don't know to be honest *10.* I think they get extra training than we do *11.* Well like we said the guidelines say the women should be referred to an FGM clinic. I don't know what they do in these clinics, as far as I know they do all the care planning there. Obviously I look at the woman's notes after but yeah, I don't know what goes on there		
01. I don't think women feel like they're being controlled at all. The women understand that the practice is wrong. I remember a woman who I met with about 15 years ago who had arranged for her daughter to be cut. A few families had arranged for a cutter to be flown over to the UK to cut a few girls. The woman regretted having her daughter cut and went to the police to tell them what had happened. The case was referred to social services and the social services decided that it was not in the best interests of the child to be removed from the family home because they considered it [FGM] as a one-off form of physical abuse. They also said that they did not consider it in the best interests of the child to remove the mother as they believed that the child had an otherwise loving environment. It makes me wonder how many times and how many children have slipped through the net		
01. we have no choice, they have to refer all women who have had FGM.I think that it is safest for all that they make the referral. I don't really discuss the referral with the women anyway because what	**Service provision and**	**Antenatal Care** **Risk Assessment**

Data	Overarching Theme	Dominant Discourses
can we do? Isn't it the law that we have to make the referral? Whether the woman likes it or not they have to refer them to the FGM clinic and to the safeguarding team. I suppose it depends on safeguarding whether they refer them [the women] to social services. I don't remember anyone being referred to social services though	**statutory regulation**	**Accountability** **Cultural Care**
01. we have to follow the guidelines and any kind of referrals made are dictated by whatever guidelines say. If we start ignoring the guidelines then what's the point of having them? Guidelines are based on evidence of what the best care is. So we follow these because it has been proved that this is the best thing to do. Guidelines aren't just thrown together, they are collected by best evidence that's why it's called evidence-based practice *02.* if it's in the guidelines to make the referral, then that's what we have to do. It's up to the woman or not whether she goes, but thinking about it, if it's something to do with safeguarding and she doesn't go to the clinic, I'm thinking safeguarding are informed anyway *03.* In investigations, I know notes are scrutinised against guidelines, I've seen it and I've been involved in doing so many investigations where the care is compared to what's in those guidelines. If someone hasn't followed them to the letter then they are hauled over the coals! But these investigation show whether we have given safe care or not, you know, the five questions and that. *04.* I don't think there's a difference at all! I can't even see why one's called policies and one's called guidelines to be honest because to us, policies and guidelines are the same because we are judged on all of it. If we don't follow the guidelines like policies then we know about it! *05.* Yes, they might be called guidelines but we don't have a choice whether we follow guidelines or not. If the guidelines say that the woman should be referred then we refer the women. If we didn't refer a woman, then someone else would. Even if I see a woman in say antenatal clinic at 36 weeks, I would still have to refer the woman if she was picked up then		

Data	Overarching Theme	Dominant Discourses
06. usually when women come in in labour they already have a birth plan that's been done in the clinic or by the community midwife. Although we can't always stick to it, sometimes the birth plan goes out the window because of things like failure to progress or abnormal CTGs and things like that. *07.* I do think that it's a nice idea but at the end of the day, our job is to make sure we have a well mum and a well baby. We have to assess that risk all the time and sometimes that means we can't see other women as much as we'd like to. Can you imagine the CQC if we had to explain that one on one of the five questions? *08.* The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *09.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *10.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it *11.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this.		
01. So I know that there is a clinic over in [place] but that's it really around this area isn't it? Although we are all expected to do it, actually, I'm not sure you midwives are as expected to do it as us lot [laughs] but yeah, if a woman comes in in labour, then if we are on [pause] although I would probably defer to the senior reg [laughs]. But seriously, if we are talking about pre-pregnancy, I only know of [name] clinic because deinfibulation is quite specialist so they are concentrated in areas like London aren't they? I'm guessing that there is a bigger population of FGM women there, I don't know [pause] I'm not sure of the need around here, I might be wrong.		

Data	Overarching Theme	Dominant Discourses
02. The trouble is, you're talking about a really small number of women compared to the number of women who actually access the services. I do know about [name's] clinic but that's the only one really in the Midlands isn't it? To be honest, I don't think there's any services really that's specific to FGM survivors other than [name's] service anywhere near here because its quite niche isn't it. So it wouldn't be a priority for the NHS budget I reckon considering all the other things that are really important like diabetes and smoking which seem to be the hot topics at the moment *03.* pre-pregnancy care isn't just about deinfibulation is it? Surely these women would need some kind of conception advice, especially type III women? Also, what about smears and other sexual health? *05.* Ok, so what I understand the vulnerable women midwives looks after women who are vulnerable, like mental health issues, teenage pregnancy, drug users and all things like that. *06.* Yes, I think they do all the safeguarding stuff in the clinic for the women and the ones that need type III opening is sorted there as far as I know, that's it but the safeguarding bit is important. To be honest, apart from the opening thing, I don't know how they are different from our vulnerable women clinics		
01. Well, yeah, that's a really nice and in theory it would be a great idea, but who would do it? There aren't enough midwives or doctors as it is to cover one shift on delivery suite let alone start offering extra services like that *02.* I can see that as well. What about talking to women after they have delivered? Would that be a better option than creating a whole new service? The women are already there and wouldn't have to go back in to talk about it. Come to think of it, they might not be bothered to come back or might be too busy with their new baby *03.* There is no way that I would have time to talk to women after delivery. I mean, well I just wouldn't have time to sit and talk about anyone's labour and delivery because when I'm on shift I have to cover more than just delivery suite, I am spread out really thinly and I could be needed anywhere in		

Data	Overarching Theme	Dominant Discourses
the hospital. So I could be half way through a debrief with a woman about her labour and that and be called to an emergency at the other end of the hospital. That would take priority. *04.* See the doctors wouldn't have time and neither would the midwives, there just isn't enough of us to do something like that. I mean [pauses] for example, [pauses] yes, when I'm on delivery suite, I could be looking after a labouring woman and as soon as she has delivered I would have to go to another woman straight away. So there isn't time to sit with people and go through it afterwards.		
01. I don't think [pauses] I think that women don't want to say about their FGM at booking because of the referrals they know we will make. With all the hype in the news about FGM I think they are scared to talk to us about it. But really, all we want to do is make sure that they have the support they need, and their pregnancy and delivery are safe.		
01. Well, yeah, that's a really nice and in theory it would be a great idea, but who would do it? There aren't enough midwives or doctors as it is to cover one shift on delivery suite let alone start offering extra services like that *02.* There is no way that I would have time to talk to women after delivery. I mean, well I just wouldn't have time to sit and talk about anyone's labour and delivery because when I'm on shift I have to cover more than just delivery suite, I am spread out really thinly and I could be needed anywhere in the hospital. So I could be half way through a debrief with a woman about her labour and that and be called to an emergency at the other end of the hospital. That would take priority. *03.* See the doctors wouldn't have time and neither would the midwives, there just isn't enough of us to do something like that. I mean [pauses] for example, [pauses] yes, when I'm on delivery suite, I could be looking after a labouring woman and as soon as she has delivered I would have to go to another woman straight away. So there isn't time to sit with people and go through it afterwards. *04.* I do think that it's a nice idea but at the end of the day, our job is to make sure we have a well mum and a well baby. We have to assess that risk all the time and sometimes that means we can't see		

Data	Overarching Theme	Dominant Discourses
other women as much as we'd like to. Can you imagine the CQC if we had to explain that one on one of the five questions? *05.* Unfortunately it's a problem that we can't solve. It will always be like this so unless we have more midwives it will always be like this *06.* Going back to women feeling like they are left alone. When we are allocating midwives to a shift, it depends how busy delivery suite is as well, that is the biggest factor here so if there are more women in labour than midwives, which happens a lot, then midwives have to be pulled from postnatal wards which always leaves them short but on the balance of risk we don't have a lot of choice. It all boils down to [pauses] at the end of the day, our first priority is to make sure everyone is safe which means everyone so that goes for the midwives as well, we have to make sure that they are safe *07.* Most definitely yes! I don't want to lose my pin number because of the amount of women I have to look after on delivery suite! It's too dangerous on delivery suite sometimes to not pull the postnatal midwives! The other thing [pauses] well, postnatal care isn't called the 'Cinderella service' for nothing! Sometimes there can be only one midwife to quite a few women, sometimes 10 or 11 who also have babies and all those women and babies, they should have a postnatal check every day and then go through a checklist when they go home but that's it unless they have any problems. So I do understand how they have it as well		
01. I don't think there's a difference at all! I can't even see why one's called policies and one's called guidelines to be honest because to us, policies and guidelines are the same because we are judged on all of it. If we don't follow the guidelines like policies then we know about it! *02.* theoretically, policies and guidelines are different, but in this line of work they may all be called policies because we have to follow them whatever		

Data	Overarching Theme	Dominant Discourses
03. Yes, they might be called guidelines but we don't have a choice whether we follow guidelines or not. If the guidelines say that the woman should be referred then we refer the women. If we didn't refer a woman, then someone else would. Even if I see a woman in say antenatal clinic at 36 weeks, I would still have to refer the woman if she was picked up then *04.* Well like we said the guidelines say the women should be referred to an FGM clinic. I don't know what they do in these clinics, as far as I know they do all the care planning there. Obviously I look at the woman's notes after but yeah, I don't know what goes on there *05.* I think yeah, safeguarding is important for these women. OK, it might not be the woman herself who agrees with FGM, but what about her family or someone else? Children have slipped through the net before, not with FGM but with other things. If we haven't referred women to the clinic and something happens, who's to blame? They would blame us for not referring her, for not following the guidelines! *06.* It depends on who the woman sees, it could be a doctor or a midwife but it will be someone who is trained to make the diagnosis *07.* but how accurate can a picture be? I think that to do proper care planning, they would need to see exactly what's happening down there. Although it's a bit worrying with that woman there [points at the screen] when the doctor got it wrong *08.* this woman looks like she felt forced into it. But I can see both points of view here, they would need to do a risk assessment of whether this woman could deliver. It would be awful if this woman turned up in labour or worst still, turned up for induction and they couldn't do it because she was type III. So yeah, I think the examinations are needed antenatally. *09.* it would mean that they can't have a normal delivery then would it? So we have to also weigh up the benefits and risks. It's better for her to have a normal delivery anyway, cus she'll recover better afterwards		

Data	Overarching Theme	Dominant Discourses
10. The law has to be discussed with the women though and there's no rooms where the women can be taken, well not at my trust anyway. But it's in every guideline and every bit of teaching that I've had on FGM that we have to discuss the law with women who are being discharged. So the postnatal midwives have got to have this conversation *14.* But there is no choice, discussing the law with FGM women is part of the pathway of care for FGM women so it's like a tick box for the guidelines if you like, although I can see how this looks. *15.* The trouble is, we have to follow the guidelines on these women because a lot of the information is tied to legal so its important they understand it *16.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this.		
01. I think it's difficult with FGM women because an FGM midwife isn't a mental health specialist and a mental health specialist midwife isn't an FGM midwife. I don't know but as far as I know a mental health midwife will get the same FGM training as the rest of us and an FGM midwife will get the same mental health training as the rest of us. I don't know any different so someone correct me on that [pauses]. So really I don't think either of them could look after the other's area better than the rest of us *02.* I agree and well, mental health assessment needs to be done by the GP so when women raise mental health concerns, guidelines tell us to refer them to their GP *03.* at the minute if we pick up mental health issues we would refer to the GP. Well, that's what our guidelines say anyway and I would follow that because there is nothing in the guidelines about referring between the two midwives *04.* I'm just thinking, so, if these midwives look after mental health women, why can't they do the mental health care for FGM women as well? Although, I would worry about those like [pause]	**Mental health care and issues**	**Antenatal Care** **Risk Assessment** **Accountability** **Cultural Care**

Data	Overarching Theme	Dominant Discourses
especially with the woman earlier with PTSD. So it's a good idea but mental health care for FGM women, that would need to be specific wouldn't it? Like trauma counselling?		
01. I just wonder how much damage has been done to these women, especially in women with PTSD like this woman. What she really needed was some support. This just shows that there needs to be more, I don't know, mental health support for FGM women. *02.* it might not be because of the FGM had it? It might be because of moving here and being isolated, or like the woman with PTSD because of deinfibulation. I think there are so many things that could cause a woman to need support, we just have be better at knowing why she needs support. *03.* I think it's difficult with FGM women because an FGM midwife isn't a mental health specialist and a mental health specialist midwife isn't an FGM midwife. I don't know but as far as I know a mental health midwife will get the same FGM training as the rest of us and an FGM midwife will get the same mental health training as the rest of us. I don't know any different so someone correct me on that [pauses]. So really I don't think either of them could look after the other's area better than the rest of us *04.* I'm just wondering though, what about if the midwives were in the same place so one could knock on the door to other, that kind of thing? And couldn't there be something joined like mental health and FGM? Like both specialist midwives doing training about it or something? *05.* I'm just thinking, so, if these midwives look after mental health women, why can't they do the mental health care for FGM women as well? Although, I would worry about those like [pause] especially with the woman earlier with PTSD. So it's a good idea but mental health care for FGM women, that would need to be specific wouldn't it? Like trauma counselling? *06.* But that's assuming that all women with FGM have PTSD, we can't assume that *07.* are we saying that all women are traumatised? Really? Maybe there are some women traumatised, but the question is why are they? The woman earlier sounds like she was more traumatised by the		

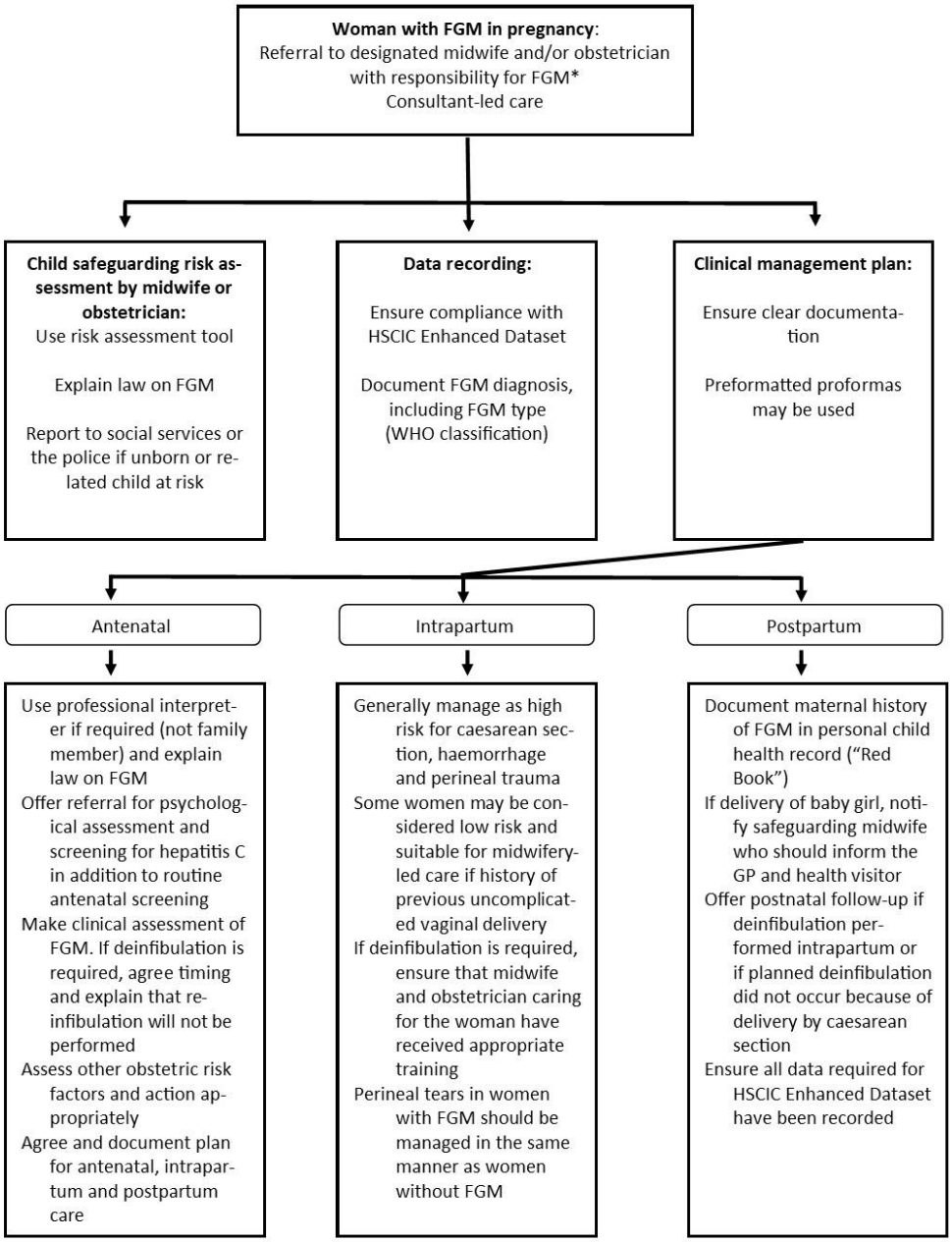
Data	Overarching Theme	Dominant Discourses
deinfibulation and it sounds like the counselling just made it worse! So joint training, yeah, which would help us understand but it doesn't help the women does it? A joint clinic might work though. I think that's a good idea *08.* Well, from my point of view, I think the guidelines need looking at if that's the most important thing there is. No wonder some of these women [pauses] well, I think and I wonder how much damage is being caused to these women because of this.		

Appendix XII
FGM Survivor Participants' Characteristics

Name	Country of Origin	Parity	Gender of baby	Type of FGM	Type of birth	Birth trauma	Comments
FS01	Yemen	0+1	Female	2	Normal	Vaginal lacerations	Long history of depression and low mood controlled by antidepressants via GP
FS02	Yemen	0	Male	1	Normal	None	
FS03	Somalia	0	Male	1	CS	None	Needed a crash caesarean section due to fetal compromise
FS04	Somalia	3+1	Male	3	Normal	2nd degree	Previous defibulation. Declined repair of tear
FS05	Somalia	0	Male	1	Forceps	3A	Living in safe house due to concealing pregnancy from husband's family
FS06	Yemen	0	Female	2	Ventouse	Episiotomy	Teenage pregnancy
FS07	The Gambia	0	Male	2	Ventouse	Episiotomy	Was diagnosed during pregnancy as type II but originally type III deinfibulation. Tight band between labia – possible spontaneous reinfibulation
FS08	Somalia	0	Male	3	Normal	2nd degree	Had defibulation 2 years previously
FS09	Yemen	5	Male	Unknown	Normal	None	Did not consent for inspection. Knew what type of FGM she had
FS10	Yemen	3+1	Female	1	Normal	None	Was admitted to HDU due to recurring sepsis
FS11	Egypt	0+4	Male	1	CS	None	Category 2 caesarean section due to sepsis
FS12	Eritrea	0+1	Male	2	CS	None	Category 2 caesarean section due to sepsis

Name	Country of Origin	Parity	Gender of baby	Type of FGM	Type of birth	Birth trauma	Comments
FS13	Sudan	4	Male	3	Normal	Defib	Required defibulation for delivery
FS14	Somalia	0	Female	3	Ventouse	Episiotomy and defibulation	Defibulation before marriage but required defibulation and episiotomy for delivery
FS15	Somalia	0+3	Female	3	Normal	Defibulation	Needed defibulation for delivery
FS16	The Gambia	1	Female	2	Normal		
FS17	Eritrea	0	Female	2	Ventouse	Episiotomy and defibulation	Incorrectly diagnosed. Was a type III not II. Medics said to her that FGM 'split' during delivery. FGM II would not split in this way
FS18	Sudan	3+2	Male	Not known	Normal		There was no midwife or doctor input for this woman's booking. She was only seen by a link worker so no FGM diagnosis before labour.
FS19	Sudan	0	Male	2	Ventouse	None	This woman raised a formal complaint because of the way she was treated by doctor antenatally
FS20	Somalia	0	Male	3	Caesarean Section	None	Pre-pregnancy PTSD

Appendix XIII
RCOG (2015) Pathway of Care for FGM Survivor in Maternity



*Local protocols will determine which elements of care (child safeguarding risk assessment, data recording, clinical management plan0 should be undertaken by the designated midwife or obstetrician responsible for women with FGM and which may be undertaken by other appropriately trained midwives or obstetricians.

Appendix XIV

Risk Register

Risk = Likelihood x Impact where the rating for Likelihood and Impact are scored between 1 and 5

Rating	Risk
1	Very Low
2	Low
3	Medium
4	High
5	Very High

Rating	RAG Status
1-7 (Low Risk)	Green
8-14 (Medium Risk)	Amber
15-25 (High Risk)	Red

		Potential Risk Level				
No.	**Description of risk**	**Likelihood**	**Impact**	**Potential Risk Level**	**Action to minimise risk**	**Actual Status RAG Rated**
1.	**Ethics approval** Gaining ethics approval was fundamental to commencing this study. The ethics process for this study was lengthy (application to approval was 18 months in total). The IRAS application was lost in the system and employment changes meant changes to the ethics approval due to changes in research site.	5	5	25	At the planning stage there had not been any previous studies conducted with FGM survivors in maternity care. As such, careful planning was needed to ensure that ethical approval was gained. Due to the delays in ethics approval, multiple contacts with HRA were made to gain and provide information about the study. The HRA were helpful in suggesting amendments to the participant information sheets as well as to the consent forms. By identifying a contact at HRA, the process of approval became smoother. Changing employment resulted in changing the university ethics approval. Whilst it was envisaged that this would be problematic, the University of Wolverhampton's ethics committee were swift and helpful in their response. As a result, the ethical approval from the university was amended and approved quickly to prevent any further delay.	Low

		Potential Risk Level				
No.	**Description of risk**	**Likelihood**	**Impact**	**Potential Risk Level**	**Action to minimise risk**	**Actual Status RAG Rated**
2.	**Study start** The delay in ethical approval from HRA resulted in a delayed study start. The start of data collection was delayed by 12 months due to a delay in gaining ethical approval. This meant that the data collection began four years after initial enrolment. Although the programme was completed on a part-time basis, half of the maximum time had elapsed before recruitment had commenced. As such, the writing of the analysis of the findings and writing of the thesis were all delayed.	4	5	20	There was little that could be done to minimise this risk. However, as soon as data collection began, analysis also began. Working hours were altered to ensure that there was time after working hours to collect and analyse data. However, this risk remains at medium since the PhD programme is not yet complete.	Medium

		Potential Risk Level				
No.	**Description of risk**	**Likelihood**	**Impact**	**Potential Risk Level**	**Action to minimise risk**	**Actual Status RAG Rated**
3.	**Recruitment** Recruitment was particularly problematic. Health care professionals working in the FGM clinic provided little assistance in recruitment which could have been an ideal place for recruiting FGM survivors in order for them to have sufficient time to consider the study.	5	5	25	There were no participants recruited from the FGM clinic. The participants recruited antenatally were recruited by the consultant midwife. As such, there was scope in the ethics approval to recruit women postnatally. As an action, the study was discussed with the inpatient matron with the remit of recruiting women on the postnatal wards. Participant information sheets were made available on the postnatal wards and recruitment and consent was completed outside of working hours.	Low
4.	**Study support** Although there was site approval for the study and access to the population was provided by the head of service, little support was given at the site for the study.	4	5	20	All work that was carried out on the study was completed outside of working hours to ensure that the employment contract was fulfilled.	High
5.	**Environmental resources** Lack of private space I the clinical areas to conduct FGM survivor one-to-one interviews	5	4	20	Whilst discussion took place with the inpatient matron to negotiate a private room on the ward, all FGM survivor interviews were conducted away from the ward to avoid any potential interruptions.	Low

Appendix XV
Literature search strategy

Literature search strategy

Databases we accessed via NHS gateways that are provided via library services in NHS Trusts. This was a useful tool since using this gateway, several databases are searched at the same time and organised into database collections.

Key words

Selecting key words was an important consideration for the search. Initially, the key words were based on the searches carried out for an undergraduate module. These consisted of FGM, female genital mutilation and pregnancy. However, the expansion of literature on FGM since that time yielded a result of more than 60,000,000 hits on databases. Therefore, searches needed to be refined in order to result in more manageable results.

The finalised key word search consisted of:

female genital mutilation OR FGM OR female circumcision OR FGM/C OR genital cutting OR genital mutilation OR cliteroidectomy OR infibulation OR traditional African initiation ceremonies. Although this search yielded far fewer hits than just using the term FGM, there were still 368,000 results. As such, these terms were used in conjunction with pregnancy OR maternity OR midwifery OR antenatal OR childbirth OR labour OR perinatal OR postnatal OR obstetric. These results were then entered into a database of results to determine the level of evidence quality as well as relevance to this study. A sample of this database can be found at Appendix XVI.

Appendix XVI
Extract of literature database

Reference	Summary of paper/literature	Evidence quality	Useful (Yes/No)
Abdulcadir, J. Ahmadu, F. Catania, L. Essen, B. Gruenbaum, E. Johnsdotter, S. Johnson, M. C. Johnson-Agbakwu, C. Kratz, C. Sulkin, C. L. McKinley, M. Njambi, W. Rogers, J. Shell-Duncan, B. Shweder, R. A. (2012) 'Seven Things to Know about Female Genital Surgeries in Africa', *Hastings Center Report*, 42(6), pp. 19–27. doi: 10.1002/hast.81	The report is presented as the instigation of a debate on FGM. The primary perspective appears to be a debate around the language and terminology used for the practice of FGM. The tone then moves to the labelling of FGM survivors and the distinctions of genital cosmetic surgeries and their parallel to the practice of FGM. Although there is an attempt at objectivity, it is difficult to distinguish since there is an FGM advocate amongst the authors. Their views seem to be intertwined with this report and results in it seemingly advocating the practice.	This report seems to present an argument in favour of the continuation of FGM with people who consent to the procedure (adults). However, there does not appear to be an explicit warning or renouncement of FGM in children. Nevertheless, this will be a useful addition to help to present an objective and balanced argument in the literature review.	Yes
Ahmadu, F. S. (2009) 'Disputing the myth of the sexual dysfunction of circumcised women', *Anthropology Today*, 25(6), pp. 14–17. doi: 10.1111/j.1467-8322.2009.00699.x.	This paper presents the sexual functioning of women who have experienced FGM. However, this is specific to women who have experienced FGM as part of the Bondo rituals. The paper argues that sexual dysfunction is not experienced by those who have experienced FGM during Bondo rituals because some clitoral tissue remains and orgasm results from vaginal penetration rather than clitoral stimulation. However, this does not take type 3 FGM into account where infibulation renders vaginal penetration impossible in most cases.	This is a subjectively written paper from the perspective of a Sierra Leonean Bondo initiate. As such, there is an overwhelming tone of advocating the practice of FGM in terms of social cohesion. This would make a good addition to the literature review in terms of activism inside the culture.	Yes

Reference	Summary of paper/literature	Evidence quality	Useful (Yes/No)
Assaad, M. B. (1999) 'Challenging the Terminology and Overcoming the Culture of Silence', *Reproductive Health Matters*, 7(3), pp. 126–127.	This was an opinion piece which discussed the use of the term 'genital surgery' in relation to FGM. Furthermore, there is discussion around the silence that exists amongst those who practice FGM and describes a 'culture of silence' where women are socialised into accepting FGM as part of their life.	This opinion piece was a good example of the conflicts around the terminology used for FGM. It was particularly interesting in terms of the debate on using genital surgery and the word *surgery* being seen to add respectability to the practice. This is a really useful addition to the literature review (particularly in terms of the critique of language used for FGM).	Yes